DOCUMENT RESUME

ED 247 676 EC 170 010

TITLE	Report of the Surgeon General's Workshop on Children with Handicaps and Their Families. Case Example: The Ventilator-Dependent Child.
INSTITUTION	Children's Hospital of Philadelphia, Pa.; Health Resources and Services Administration, Rockville, MD. Bureau of Health Care Delivery and Assistance.
REPORT NO	DHHS-PHS-83-50194
PUB DATE	Dec 82
NOTE	82p.; The document was also supported by grants from the Widener Memorial Foundation and Heron Respiratory Services, Inc.
PUB TYPE	Collected Works - Conference Proceedings (021) -- Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Demonstration Programs; *Disabilities; Educational Needs; Financial Policy; Health Needs; *Medical Services; Premature Infants; Program Descriptions; *Special Health Problems
IDENTIFIERS	*Ventilator Dependence

ABSTRACT

The booklet presents papers from a December 1982 workshop on specific problems in caring for ventilator-dependent children (children with respiratory distress due to prematurity, low birth weight or developmental immaturity). Following excerpts from the keynote address by C. Everett Koop, the U.S. Surgeon General, model programs from Pennsylvania, New York, and Illinois are described. A mother of a ventilator-dependent child with multiple birth defects presents the parents' viewpoint. Recommendations from 10 work groups combining parents, professionals, policymakers and others focus on organizational and financial considerations. Among recommendations made are for developing regional systems of care, developing model standards for quality assurance, and incorporating principles of care for children with disabilities into format education curricula. (CL)

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REPORT OF THE SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES

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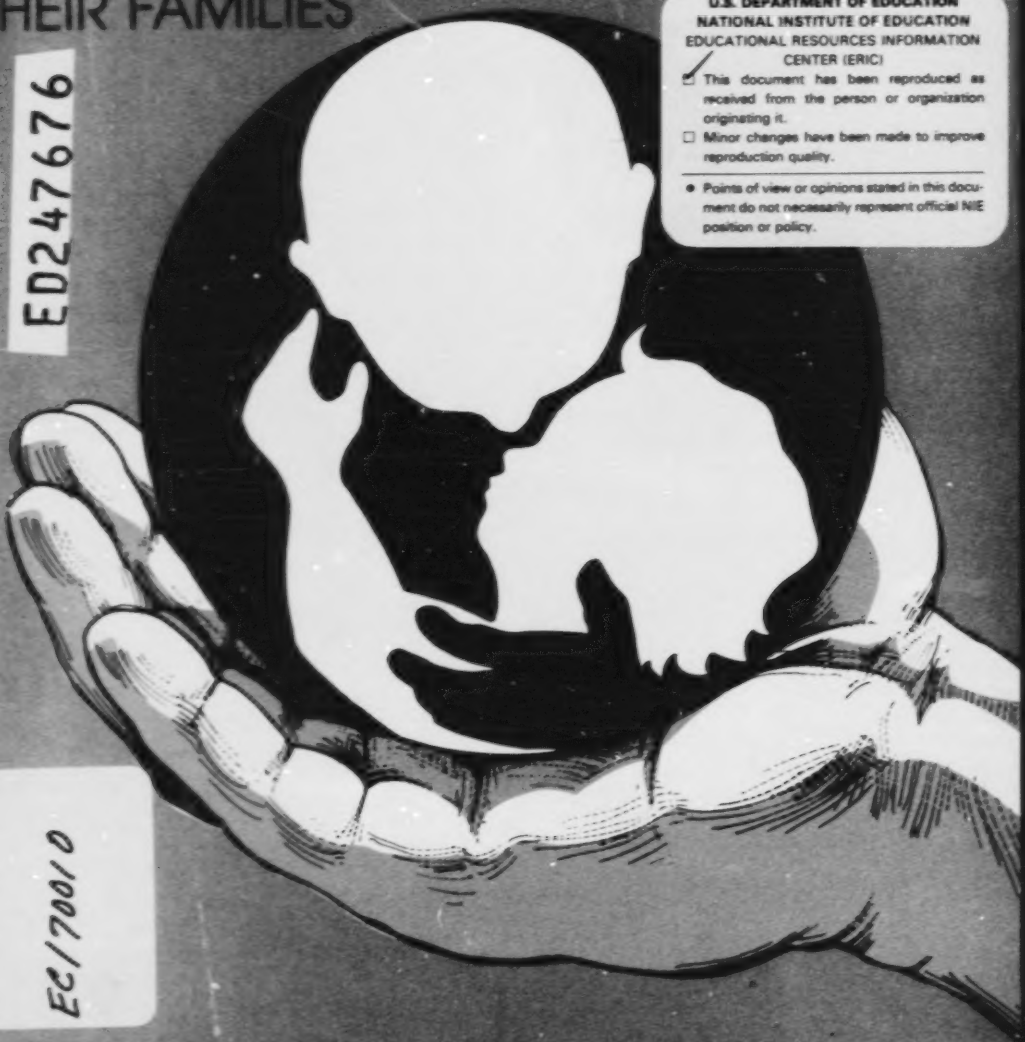

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service

2

THE WHITE HOUSE

December 10, 1982

Dear Friends:

This brings my special greetings to each of you participating in the Surgeon General's Workshop on Children with Handicaps and Their Families.

I want to encourage you in this very important endeavor. For many children facing physical difficulties, there is no place like home and no substitute for being close to a loving family. I am hopeful that ways can be found to make it possible for many more children on life-supportive devices to go home. It will mean more than we know to both the children and their parents. The entire family will derive untold strength from being together.

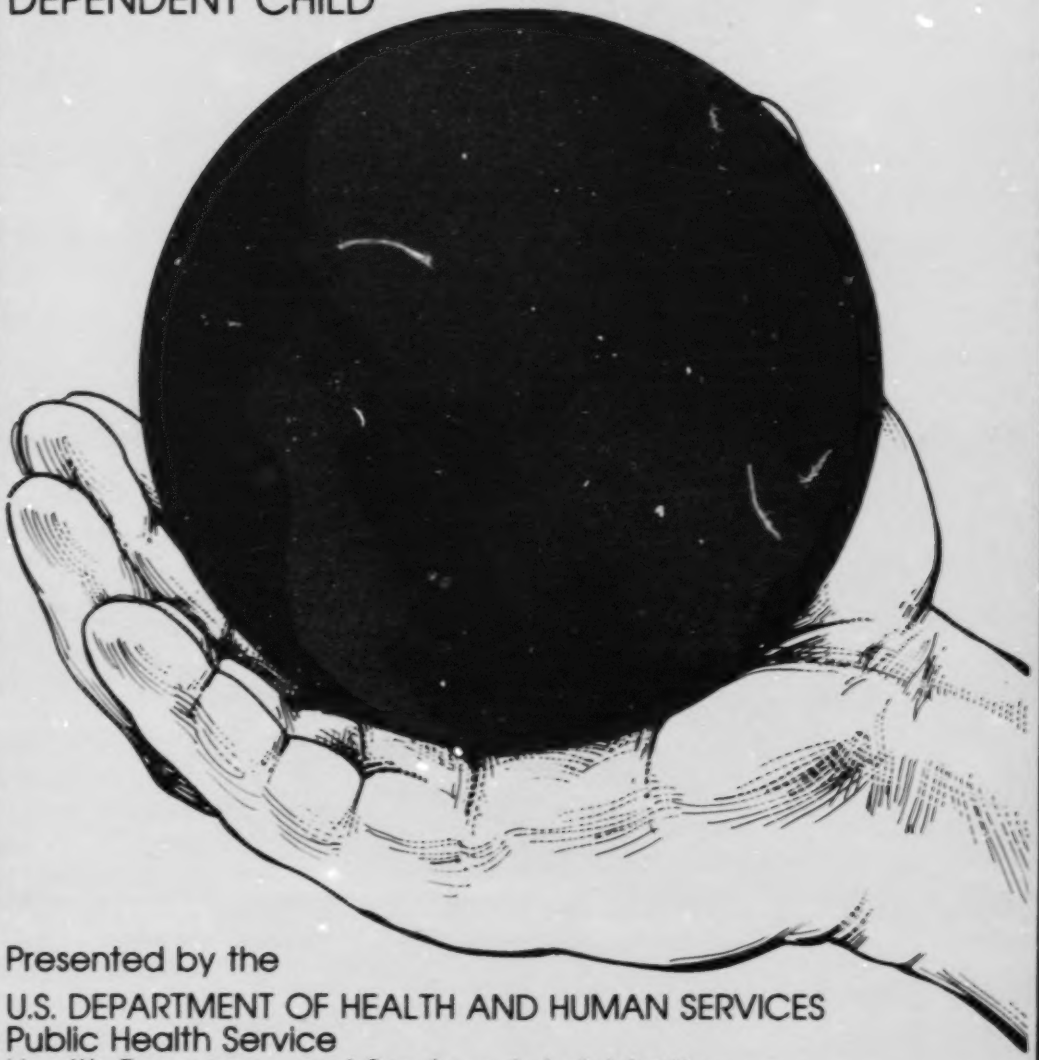
I thank you from the bottom of my heart for your interest in helping our special children. You have my warmest best wishes for a successful workshop.

Sincerely,

Nancy Reagan

The Surgeon General's Workshop on
Children with Handicaps and Their Families
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania

REPORT OF THE SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES CASE EXAMPLE: THE VENTILATOR-DEPENDENT CHILD



Presented by the

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Health Resources and Services Administration
Bureau of Health Care Delivery and Assistance
Division of Maternal and Child Health

In Conjunction With
THE CHILDREN'S HOSPITAL OF PHILADELPHIA

DECEMBER 13TH AND 14TH 1982

DHHS PUBLICATION NO. PHS-83-50194

It is profoundly important for our society that we tend to these issues of disabled children, that these children not be forgotten or pushed aside, and that we retain our belief in the strength of the American family.

—C. EVERETT KOOP, M.D.
SURGEON GENERAL

The Surgeon General's Workshop on Children With Handicaps and Their Families was supported by grants from the U.S. Department of Health and Human Services, The Widener Memorial Foundation, and Heron Respiratory Services, Inc.

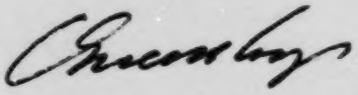
Photos Courtesy of The Children's Hospital of Philadelphia

PREFACE

The Surgeon General's Workshop on Children With Handicaps and Their Families recognizes our continuing interest in assisting the family as the prime source of nurture, support, protection, and guidance to the growing child. Children with handicaps and their families frequently require long-term medical, social, educational, vocational, habilitative, and community service assistance. This concept is essential to the provision of comprehensive services to children with special needs.

Families of these children, including siblings, often need significant psychosocial support, but community support services are often lacking or not visible. Without the needed support, the family will have difficulty in helping the child, a growing individual moving through predictable developmental stages, achieve maximum development within the limitations imposed by a disability.

The goal of the participants at this Surgeon General's Workshop was to develop recommendations for strategies to recognize the special burden and challenges borne by the parents and siblings of children with disabililties and to stimulate the provision of resources to safely support these children in their communities. The achievement of this goal will, ideally, minimize the problems of children with disabilities.



C. Everett Koop, M.D.
Surgeon General

7

PLANNING COMMITTEE

Planning Committee for the Surgeon General's Workshop
on Children With Handicaps and Their Families

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Division of Policy Analysis
Office for Health Planning and Evaluation
Washington, D.C.

WORKSHOP PROGRAM

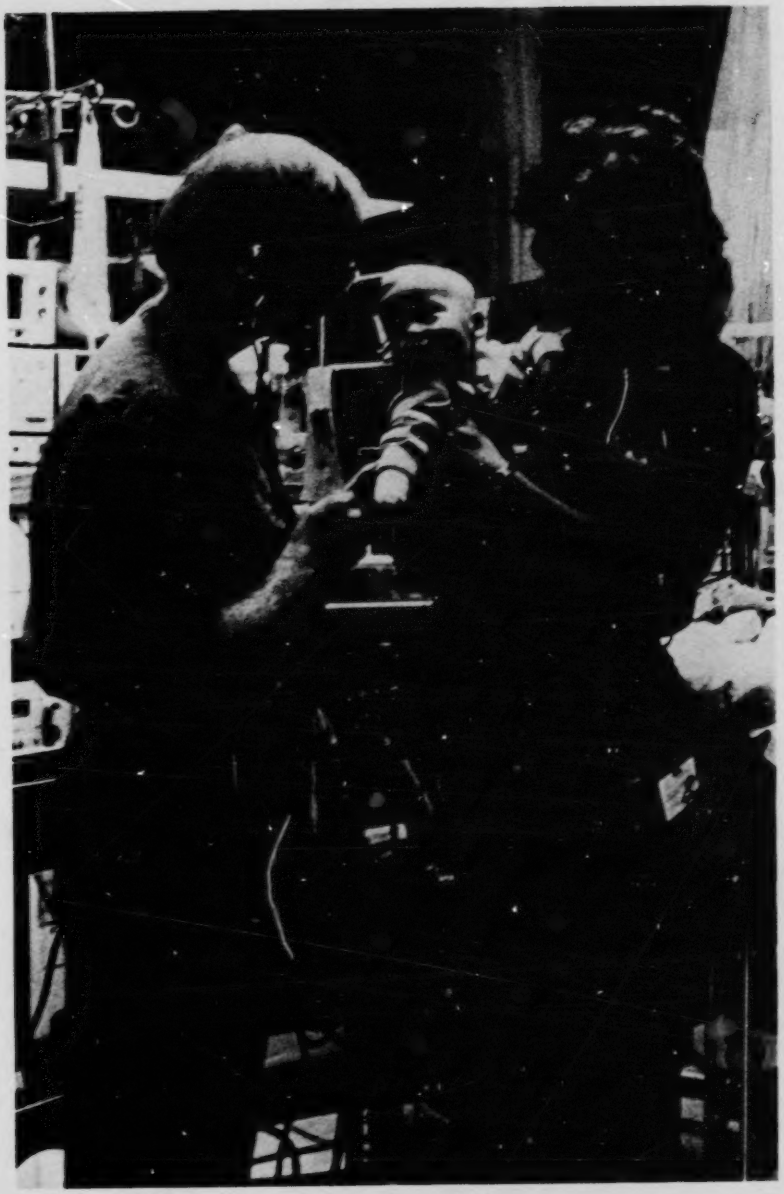
December 13, 1982

8:00 a.m. - 11:45 a.m.	Plenary Session Joseph Stokes Auditorium The Children's Hospital of Philadelphia
Presiding	Merle G. McPherson, M.D. Chief, Habilitative Services Branch Division of Maternal and Child Health United States Department of Health and Human Services—Public Health Service
Welcome	Noel E. Kroncke, President The Children's Hospital of Philadelphia
	Ginny Thornburgh Advocate for the Handicapped
	James A. O'Neill, Jr., M.D. Surgeon-in-Chief The Children's Hospital of Philadelphia
	Thomas W. Langfitt, M.D. Vice President for Health Affairs University of Pennsylvania
	Robert G. Kettrick, M.D. Director, Pediatric Intensive Care Unit Intermediate The Children's Hospital of Philadelphia
8:30 a.m. Keynote and Charge	C. Everett Koop, M.D. Surgeon General
9:00 a.m. Ventilator-Dependent Children: The Problem	Robert G. Kettrick, M.D.
9:45 a.m. The Child at Home	Mrs. Bette Wartenberg Parent of a Ventilator-Dependent Child Joliet, Illinois
10:45 a.m. Comprehensive Regionalized Care: New York Experience	Mathew H.M.Lee, M.D. Professor and Director, Howard A. Rusk Respirator Rehabilatation Medicine Department of Rehabilitative Medicine New York University Medical Center Goldwater Memorial Hospital New York, New York

11:15 a.m. Towards a Consortium: The Illinois Approach	Allen I. Goldberg, M.D. Director, Division of Respiratory Care Children's Memorial Hospital Chicago, Illinois Arthur F. Kohrman, M.D., Director LaRabida Children's Hospital and Research Center Chicago, Illinois Eugene Bilotti, Administrator Supplemental Security Income (SSI) Disabled Children's Program Springfield, Illinois
11:45 a.m. Question Period	Morning Speakers
12:15 p.m.	Luncheon Salons A and B Hilton Hotel of Philadelphia
Presiding	C. Everett Koop, M.D.
Invocation	The Reverend William Atkinson, O.S.A.
Children with Disabilities—Implications for Care	Alfred Healy, M.D. Chairman, Division of Developmental Disabilities University Hospital School University of Iowa Iowa City, Iowa
2:00 p.m. Background for Work Group Discussion	Phyllis R. Magrab, Ph.D. Director, Child Development Center Georgetown University Hospital Washington, D.C.
2:30 - 5:30 p.m.	Workshops
December 14, 1982	
8:00 a.m.	Work Groups
2:00 p.m. - 5:00 p.m. Plenary Session-Summation	Joseph Stokes Auditorium The Children's Hospital of Philadelphia
Presiding	Robert G. Kettrick, M.D.
Presentations from Work Groups	
Synthesis of Recommendations	John MacQueen, M.D. Director Iowa Specialized Child Health Services University of Iowa Hospitals and Clinics Iowa City, Iowa
Presentation to Surgeon General	Robert G. Kettrick, M.D.
Acceptance of Recommendations	C. Everett Koop, M.D.
Conclusion	Richard D. Wood, Chairman Board of Managers The Children's Hospital of Philadelphia

CONTENTS

	Page
INTRODUCTION	1
WELCOMING ADDRESS	3
EXCERPT FROM KEYNOTE ADDRESS	5
PRESENTATIONS OF PROGRAMS FOR CARE OF VENTILATOR-DEPENDENT CHILDREN	11
The Pennsylvania Program	11
The New York Experience	17
The Illinois Plan	20
The Child at Home	27
WORK GROUP RECOMMENDATIONS	31
Introduction to Work Groups	31
Recommendations	32
CHILDREN WITH OTHER HANDICAPS	41
Children with Disabilities: Implications for Care	41
Implications for Care: The Title V Perspective	48
Implications of Workshop Recommendations	50
SUMMARY OF THE WORKSHOP	53
APPENDICES	
A—Participants	56
B—Facilitators and Recorders	62
C—Prototype Home Program Review for Ventilator-Dependent Children	63
D—Selected Readings	67



INTRODUCTION

The health of most American children has improved remarkably over the past two decades. Low-birth-weight or otherwise vulnerable newborns who remain in the hospital long after birth have benefited from increasingly sophisticated technology. The technology, often requiring extended hospital care, has an unwanted side effect of subjecting these infants to abnormal environmental conditions, including separation from parents. The opportunity for close parent-infant contact is limited, and parents may have problems relating to the child in a home environment.

Resources within the community have not been developed, or if present, are not organized to encourage early discharge and to assist the family in aiding their child. Those newborns with their disabilities and continuing needs are dramatic examples of a more pervasive problem. Of the unmet health care needs of American children, the needs of children with handicaps are those most deeply felt.

To promote an understanding of these needs and to develop strategies to meet them, Dr. Koop convened the second Surgeon General's Workshop at The Children's Hospital of Philadelphia, December 12-14, 1982. The Workshop on Children With Handicaps and Their Families brought together health professionals, financing experts, consumer representatives, patients and families, and local, State, and Federal Government officials for analysis and discussion of the subject.

The major objectives were twofold: (1) to examine the problem of services delivery to handicapped children and their families in order to develop strategies for providing community-based services as an alternative to acute care facilities; and (2) to examine current funding mechanisms for providing services in order to develop new strategies of improving financing for safe, appropriate, and cost-effective health care for these children and their families in nonacute care facilities.

The Workshop focused on four basic goals:

- To strengthen the families' ability to cope;
- To promote adequate support services on a community basis;
- To organize and coordinate existing community resources on a regionalized theme; and
- To identify and remove legislative, financial, and other barriers.

Following the keynote address and the presentation of model programs for care of the ventilator-dependent child, the participants were assigned to small Work Groups. Their duties were to:

- Plan an organizational approach to health care for ventilator-dependent children and their families;
- Promote family and patient autonomy for care in home or community environments;
- Develop strategies for organizing and providing this care in a cost-effective manner;
- Recommend monitoring processes for quality assurance and funding dynamics;
- Draw implications for nationwide care for all children with handicaps;
- Suggest areas for continuing study.

Because of the complexities involved in attempting to cover all handicaps, the Work Groups concentrated on the severe, specific problems of the ventilator-dependent child as a prototype for discussion. These findings were extrapolated for all handicapped children.

The participants reconvened in plenary session to present their findings and to develop a synthesis of their recommendations. Workshop Chairman Robert G. Kettrick, M.D. conceptualized the deliberations in a summation to the Surgeon General, who accepted and commented on them. This report is designed to disseminate the conclusions of the Workshop to the widest possible audience.

WELCOMING ADDRESS

Ginny Thornburgh, Advocate for the Handicapped

We are proud to welcome you from across the nation to Pennsylvania and to Philadelphia. We are particularly proud to welcome the Surgeon General back to Children's Hospital. There's no place like home.

I'm not here because I'm the wife of our governor. I'm here because I'm a mother. I'm the mother of Peter Thornburgh, who is a superbly handsome, superbly fine young man who happens to be mentally retarded. Peter would have been institutionalized had he not had superb medical care, very fine community services, and a willing family. I think that represents the kind of family we're going to be talking about here. The goal of this Workshop is to devise public and private methods for handicapped children to live as independently as possible.

We are very, very proud in Pennsylvania to have responded to the needs of ventilator-dependent children. Two years ago, I visited the unit here in Children's Hospital where I met a number of ventilator-dependent children and their moms and dads and brothers-in-law and uncles. All of these children wanted to be home. Among the children I met was my friend, Jill Eshelman, who is here today. Jill is a ninth-grader in public school in Pennsylvania and now lives at home with her mom. That's possible in Pennsylvania, and it's going to be possible in your State also, I hope. But the ventilator-dependent children are only the tip of the iceberg. Solving that problem alone won't solve the problems of handicapped children.

There are going to be three things that are necessary, in my opinion, to allow handicapped children to live as independently as possible.

First of all, we've got to get physicians and health planners to be willing to respond in a creative way—not just the old tried and safe ways but in ways that are new and exciting and right.

Number two, the advocates. That's what I call myself. Do you remember in reading about Socrates the word gadfly? I love that word, and I consider myself a gadfly on the system. Advocates today have to be politically realistic. Solutions to the problems of the 80s are not going to happen just because they are right or just or compassionate. They also have to be sound fiscally. The advocates of today have to be smart politically and seek their goals in a sound political way.

Number three, the general citizenry, the people of the nation. The people have to be willing to become educated. There is a lot to learn about disease and health and syndromes and medical care. The citizenry has to be willing to learn, and you and I have to approach them on their level. If we don't elevate the educational level of the citizenry, the legislators are not going to vote the funds for us to get our programs through.

The parents, too, have to be willing to take a risk. I know that. I've done it with my son, time and time again. Risky decisions were made, and I was willing to say "yes." Two years ago, I was willing to say "yes" when he moved out from under my wing to a group home in the community. Try that when you're a mom or dad and when you know what the system's like. It's tough. But it's working. Peter Thornburgh, [illegible]hat you'll know how fine he is, is a very dependable person. He [illegible] rides the public bus, transfers, rides another bus. He now cooks scrambled eggs for himself, turning on the burner. You know, I never would have let him turn on the burner at home. And last night, he called his best girl in Pittsburgh and asked her if she bought a new dress for the Inaugural Ball. So thanks to good policy and thanks to a community that was available when we needed them, Peter Thornburgh is an independent man.

You have a task that is not pie in the sky. No more of that. We need a blue-print for action, something Dr. Koop can present to the Nation to allow disabled children to become as independent as they can.

EXCERPT FROM KEYNOTE ADDRESS

C. Everett Koop, M.D.
Surgeon General and Deputy Assistant Secretary for Health

Our task at this Workshop is not an easy one. We are asking each other to deal with very complex issues as we keep in mind the many levels of complexity: the *emotional* and the *moral*, the *medical* and the *technological*, the *social*, the *psychological*, and the *financial*.

Of course, we won't be explicitly attending to each of these levels always. But we know they are there. When we talk about "cost-effective life-support systems," we are implicitly putting some dollar value on a human life. We may not want to admit it, but that's certainly one outcome. So the moral and the technological and the economic do come together, whether or not we feel comfortable about it.

There is yet another complication. The lives we are concerned with at this Workshop are new lives. We are able to interact with them, but there is a clear limit to this interaction. We know, for example, that there can be no true "informed consent" with a newborn. So we must turn to the parents of those new lives and assume a joint responsibility through their understanding and consent.

I think it is essential for the attending physician, in particular, to sit down with the family and carefully go through the nature of the infant's condition, what the medical experience with such a condition has been so far, what kinds of options are open for immediate action, and what kinds of options may be open to the family and the physician later on.

It would be a mistake for me to dwell entirely on the potential hurdles and barriers to the care of disabled infants and children. The overwhelming direction of infant and child health in this country is toward improved care and better outcomes.

The infant mortality rate is still declining: the provisional rate for the 12 months ending in July, the latest figure we have, stands at 11.3 infant deaths per 1,000 live births, the lowest 12-month rate in our history. There had been some feeling in the past year or so that we were hitting a plateau, that the curve would begin to flatten out and we would have to begin dealing with the hard-core issues affecting perinatal care in this country. But the curve is *not* flattening out. It is still going down at about the same angle and we have not yet hit any infant mortality rate that is, for our society, the irreducible minimum.

Of equal significance is that most of the infant lives we are saving are *healthy* lives. There is no real evidence so far that the infant *morbidity* rate goes up as the infant *mortality* rate goes down. But, in all candor, we have not done the kind of research that's required in order to elevate this conclusion above the level of what it really is: our best instinctive, visceral response to the data.

Of course, we don't need statistical curves that go sharply up or down to understand the impact a disabled infant has upon the parents and upon the attending medical and social services staffs. Giving birth is a highly complex emotional, psychological, and physical event, even when a healthy baby is delivered. How much more complex it can be when the infant is disabled. All the persons involved—the family and the hospital staff—they all share the feelings of guilt and inadequacy.

But medicine and social service cannot take the place of the family. Rather, the professionals should use their talents and expertise to help the family survive and function, to renew its strength and foster its cohesion. For it will be the family that will provide the long-term help required by the disabled infant. The family's daily decisions, routines, and relationships will translate into the support, the therapy, the special education, the recreational efforts, and all the other aspects of the best possible quality of life for the disabled child.

The overwhelming number of parents of handicapped newborns—over 95 percent—take responsibility for their children, take them home, and try to absorb them into their family life. Our challenge is to help those parents understand, love, and care for their child.

As I indicated earlier, even if they do get the best possible guidance, disabled infants and their families may still face a future of enormous human challenges in their communities and in their own homes. How much more difficult their lives will be, then, if the initial help they receive from the hospital staff is not the very best that's available. Staff excellence, therefore, must form the basis of all our procedures, routines, and work plans.

Consensus of Principles

A good staff is open to the needs of its patients and draws liberally from the strengths of its own members. A good staff operates on a consensus of principles that form the basis for the way we care for our disabled patients and their families, and, I believe these few principles do have a strong though unspoken power among us.

The first principle is to *obtain open, direct, and personal communicatons with the parents of a disabled child.*

When an infant is born with Down syndrome, spina bifida, some congenital defect, a damaged organ system, a missing or deformed limb, or one of any number of disabling conditions, the physician-patient relationship is no longer casual. It cannot be flip. And it won't be short-term. The physician has to translate the complicated medical terminology into words the parents can understand—and not fear.

There are ways to train medical staff—physicians of *all* ages, I might add—to settle down to a close, compassionate, highly personal, and possibly prolonged relationship with parents who may be setting out on a long and intricate journey in human growth. Young physicians especially need this kind of training. They will have just come from an educational system that measures success almost exclusively in terms of curing and repairing patients and returning them to a normal state. But many disabled neonates cannot be "cured" or readily "repaired." They may never approach what might be considered a "normal" state of functioning at any time in their lives—and their lives may be very brief.

A second principle practiced by an excellent staff is this: *the staff must recognize and understand the natural responses of parents to their disabled baby* . . . their feelings of sadness, guilt, anger, even of shame. Parents' questions may come in a rush, but the answers must be given only after a great deal of careful thought. The staff now represents not only medical care—but the outside world as well. In such intense human situations, a staff has many assignments and few choices. No matter how serious the infant's condition, it is essential that staff members not transmit in any way a sense of hopelessness or futility, or in effect, go into mourning for a child who is still very much alive, however severe the physical or mental burden.

We are outraged at parents who physically abandon their children . . . and I am outraged at physicians who intellectually abandon their patients. No matter how sophisticated our diagnostic technology, it can *still be wrong.* By the same token, the survival power of the human being—even in the tiny newborn state—can be truly awesome. We need to transmit this understanding to parents, even as they verbalize their most troubling thoughts.

But I have a particular *caveat* to raise here. I want to emphasize that restraining oneself from speaking in terms of hopelessness is *not the same thing as offering false hopes* to confused and frightened parents. We need to be cautious, honest, and objective with parents. And we need to build on their strengths.

At this time we do not have a clear idea of the number of mothers who take home infants born with single or multiple disabilities . . . who try to absorb the information about the care they need . . . or who try to cope with all the attendant problems—but who ultimately decide to surrender their children for adoption or institutionalization.

It has been my experience that many of these decisions to give up a child were made by parents who would have been rewarded a hundredfold if they had not given them up but instead had held on for just a little longer and had been given just a little additional support. The child, in the overwhelming number of such cases, would also have had a chance at a more fulfilled and fulfilling life.

The third principle emphasizes the *full participation of the parents and siblings in all the processes of medical care.* In as many ways as possible, a staff needs to demonstrate to the parents that they are needed as partners. It is not artificial, not some ruse to trick them into doing something they ought not to do. Quite the reverse. There is no substitute for loving, caring parents.

As soon as possible, the physician and other staff members should try to get the child literally into the hands of the family. A parent staring through a pane of glass at a little baby in a covered isolette over in the corner is not my idea of "family togetherness." Even though the baby may be bandaged, intubated, monitored, and fed with a hyper-alimentation line, the parents can and should touch, and . . . if possible . . . hold and cuddle the child.

As a last principle I would say that the medical and social service staffs need to *play a positive, active role in linking up the child and the family with available social and medical support groups in the community.*

In other contexts and for more routine situations we all advocate *continuity of care* and *total care* for our patients and clients. How much more important is this kind of approach for infants with disabilities? The medical

and social service staffs who take this principle seriously have the set of mind and the firm professional commitment to become advocates for their patients and the parents. In that role, they help make the vital connections between home and community resources.

People who work in hospitals, clinics, schools, or other service institutions are usually familiar with most of the community services network—and very often they assume that everyone else has the same information. But, in point of fact, most people do not.

Most people may, on occasion, have used one or another social service or health agency or may have regularly contributed to certain voluntary organizations concerned with a particular disease or disability. But when people are faced with the immediate need to get information, apply for help, request certain resources, make connections, make decisions—much of their past experience and knowledge becomes somehow disjunctive.

If the parents and the staff have formed a relationship based upon the principles I've talked about this morning—even if they have already made a firm commitment to give their child all the care and love needed—they may still be totally overwhelmed by the byzantine complexity of our social service delivery system. Society may seem to be conspiring against their humanity.

I think it's important to remember that "social services" as such are not exclusively the province of the "social service worker." Certainly we expect a greater professionalism from a person trained in this field, but there are many other disciplines within the hospital community that can be helpful, too. I am thinking in particular of that new and extraordinary breed of individual known as the "neonatal intensive care nurse." They bring to their job a total commitment to child health and welfare . . . not in the abstract, but in the real world of day-to-day care for tiny vulnerable lives.

When we introduce the patient's family to the world of social services, we can help make good things come to pass, but we cannot *insure* that good things will come to pass. Families have rich and varied biographies. Fortunes rise and fall. Children do or do not all get along with each other. Mothers may or may not succeed in developing a strong bond with their disabled infants. Husbands and wives may or may not cleave to each other till death does them part. And the disabled infant . . . growing child . . . young adult . . . and adult are part of that evolution, that miracle of human growth. And, like all miracles, you cannot predict how this one will turn out.

That word—"miracle"—is being worked very hard these days. It tends to be used with every new development in medical technology, regardless of the outcomes. Certainly there may be much that seems to be "miraculous" about infant intensive care technology, but the outcomes are also mixed.

A New Category of Disability

I mentioned that the infant mortality rate is coming down and that, as near as we could tell, most of the babies we are saving are healthy babies. But the picture is really not that simple. A number of the infants we are saving are premature or arrive with a low birth weight or are immature in some aspect of their development and exhibit respiratory distress. They may be taken immediately to an infant intensive care unit, or transported to one,

and put on a respirator. These babies are usually the ones that might not have survived their birth just a few years ago. Today they are alive. But they represent a new category of disabled child—a category *created* by technology. The alternative for such babies had once been death.

The cost is very high, not only in dollars but in family stress as well. The child is denied the initial, vital attention of that mother. Opportunities for early bonding are gone. The entry of that child into the family is delayed . . . and, depending upon the circumstances, possibly delayed forever.

I know others on the program today and tomorrow are going to speak more particularly to this example. But I want to underscore its significance:

> *First,* the respirator-dependent child is a creature of our new technology and, in fact, needs additonal technology to relieve the state of dependency. This is no longer a unique problem for medicine. It is very useful, therefore, to take a close look at the problem of the respirator-dependent child in order to search out those concepts and approaches that may produce workable solutions in other, similar situations. The way we handle this particular problem may, in fact, be a kind of model for the way we might deal with many other disabilities that tax our human and material resources.
>
> *Second,* the problem of the respirator-dependent child concerns technology . . . but not exclusively. Fundamental to the handling of this problem, I believe, are the several principles promoting staff-family interplay. This is where technology leaves off and basic humanity takes over.
>
> *Third,* it provides us with a rather clear assessment of how adequate—or inadequate—our social services may be, not just for patient care but for total family care as well.
>
> And, *fourth,* it is possible for us to begin some longitudinal studies of how these patients do, both in the hospital setting and in the home, what the costs are at each place, what the effects are of changes in technology, what the cost/price history is, and so on.

Such an opportunity rarely appears in which all these four elements are present. So I am delighted to see you here, looking hard at the overall problem of providing better care for disabled children and their families, and also focusing in on the specific example—or "model"—of the care for the respirator-dependent child and the family.

Again, let me thank each one of you for coming today, for contributing your time, knowledge, and experience—and your basic humanity—to this problem. In the long run, I think that the way we deal with problems like this reveals just what kind of a society we are.

PRESENTATIONS OF PROGRAMS FOR CARE OF VENTILATOR-DEPENDENT CHILDREN

THE PENNSYLVANIA PROGRAM

Robert G. Kettrick, M.D.

Over the past decade we in the medical community have made tremendous technological progress in preserving the lives of the newborn. This audience, representing the health care industry, is largely responsible for providing the medical environment that enables these children to live, although sometimes with disabilities and possible handicaps. This imperfect solution is of no less importance for the legislators, administrators, and executives present than for the doctors and nurses. You also represent our society and our system of values. These disabled children are the children of our society and in that sense they are your children.

Today, in the United States, there are legitimate health care alternatives that are not available to these children and their families. You, as members of society and as contributors to the health care effort, need to insure that all reasonable alternatives of care are available.

With respect to the case model of the ventilator-dependent child, my message to you is simply this:

1. In many instances we can take better care of children and adults outside of an acute-care facility. This better care can be provided in the home at less cost than that which institutional care seems to mandate.
2. In order to provide this other legitimate alternative—home care—we need to identify and correct those circumstances which prevent its implementation.

Let me start to develop these points by sharing some of our experiences. Consider the child who has a total thoracic ectopia cordis. From a clinical standpoint, these children would not have survived. At least they never did before, but now three of these children are alive. Two are still dependent on mechanical ventilation. The first of these children remained in our hospital for just over three years with hospital charges exceeding $750,000. He then went home on mechanical ventilation, supplemental oxygen, and with a tracheostomy. During the succeeding two years at home he was eventually decannulated. During that time he commuted to a community special education program, and part-time nursing service was supplied through New Jersey's Supplemental Social Security Income/Disabled Children's Program. These were devastating times for this family, who had to struggle to provide care, work, and pursue further education.

Consider another type of patient—the premature infant. Ten years ago the infant of less than 1500 grams was likely to die. Six years ago my daughter, a 1300 gram preemie, spent one month in a neonatal intensive care unit, one week in a transitional unit, and was sent home at 1900 grams. The times have changed; more and more premature infants weighing less than a thousand grams at birth are living. Some, however, live to develop bronchopulmonary dysplasia and in many cases chronic respiratory failure secondary to that bronchopulmonary dysplasia.

Still another category of patient is represented by Chris, a child with a post-infectious demyelinating syndrome which left him ventilator-dependent. The family was educated in the techniques necessary to provide care at home and the child was discharged. Part-time nursing was provided through union insurance. At that time he had a portable, battery-operated ventilator, battery-operated suction, and a portable liquid oxygen unit. The community made resources available to take him to school and to provide for his education.

When I talk about care at home as an alternative, I am talking about the routine use of advanced life support technology in the home, in a very real sense transplanting elements of the expensive intensive care environment to the home. Can it be done? Absolutely! Can it provide better health care for the child? Absolutely! As long as you select your patients and family properly, and as long as you can find a way to pay for it.

Etiology of Ventilator-Dependency

Ventilator-dependent children fall into three categories. First, there are those with severe bronchopulmonary dysplasia, often with right ventricular hypertrophy. Originally, we accepted these patients from infant intensive care units all over the Delaware Valley. More recently, we have had to restrict our transfers to those from our owninfant intensive care unit. Their mean duration of hospitalization is 499 days, and the range is between 285 and 1,250 days.

The second group are those children with neuromuscular disease. The children with severe infant botulism are particularly satisfying to work with. They all get better, but it may take 3 to 6 months to wean them from mechanical ventilatory support. These are children with severe motor impairment whose cognitive potential generally is not affected. Eventually, all of these children have their care transferred to a home environment. However, effecting that transfer is time-consuming as evidenced by their own mean duration of hospitalization—214 days.

The third group of children consists of those with congenital anomalies directly associated with chronic respiratory failure and those anomalies whose management was associated with complications producing chronic respiratory failure; e.g. esophogeal stenosis, tricuspid atresia, and pulmonary atresia. For this group, corrective surgical procedures, growth, and development usually allow eventual independence from mechanical ventilatory support. The mean duration of hospitalization for this group is 198 days.

Because of limitations of skill and knowledge inherent to our "state-of-the-art" medical and surgical expertise, results are often supportive rather

than curative. We have achieved a patient population which would not have survived before the regionalization of medical services; part of the achievement comes from efforts at the local care facility to stabilize and to transport the infant to tertiary care facilities. The intensive care environment, with its technological sophistication, its surveillance by nurses and physicians, and its rapid responsiveness to patients' needscontributes to chronicity. Both public and private financial support have underwritten this medical effort and therefore have contributed to the survival of patients with chronic respiratory failure.

Disposition

There are a number of possible disposition alternatives for the child requiring long-term ventilatory support. First, the intensive care unit. It is expensive—approximately $250,000 per year. It forces separation from the family. It exposes the child repeatedly to stressed personnel, stressed families, and gallows humor along with catastrophic deaths, bloody intervention, and group assault. It is a terrible place to grow up, but grow up these children do. Currently 9 of the 28 beds in our acute care facility are occupied by children with chronic respiratory failure. There have been times when 16 of our 28 intensive care beds were occupied by such children.

Yet, the chronic care facility or extended care facility for ventilator-dependent children doesn't exist. Why? Ventilator-dependent children are a relatively new problem, and many people don't want to believe the problem exists. Many see death as a more cost-effective alternative; many see death as a more humane alternative. Many are scared by the economics and the experience with dialysis. However, the reality is that this patient population does exist and will continue to exist. Extended care facilities may have to be developed.

The acute care hospital intermediate unit is an essential step towards successful implementation of home care. The pediatric intensive care intermediate unit of The Children's Hospital of Philadelphia has evolved into a community where ventilator-dependent children come to live while we begin to sort out their medical and social needs. The unit has adapted a plan for the support and protection of the ventilator-dependent infant. It recognizes that:

1. The responsibility of the medical community is to provide an environment that will support and protect the child from those phenomena that will adversely affect organ, system, child, and family growth and development.
2. The natural history of each of the diseases which produce chronic respiratory failure largely dictates the rapidity and/or possibility of wean.
3. The child belongs to the family. Medical paternalism is actively discouraged. We have a goal of an integrated family with a strong parental sense of responsibility for the care of their child.

The environment for these children is very important. Efforts are directed towards providing a warm, humane, and stimulating environment. Noninvasive technology and treatment are stressed. For example, respiratory

status is assessed using impedence pneumograph, capnograph, transcutaneous oxygen analysis, and clinical presentation. Blood studies are drawn primarily to provide support for presumptive diagnoses, not for routine screening. Drugs are administered enterally. Intramuscular injections are avoided since they are painful, and their cumulative effects have been associated with muscle fibrosis and limitation of motion.

We try to provide a normal rhythm to the day. After the lights are turned on in the morning, there is a pattern of bathing, tracheostomy care, dressing, feeding, and so forth. Lights are dimmed for naps and consultants are encouraged not to disturb these naps. Parents can be with the child at any time, and other family members are encouraged to visit and interact with the child. The hospital is home for these children, and the environment should reflect such an atmosphere as much as possible.

The transfer of an infant to a unit for chronic ventilatory support can produce significant stress for the family. The caregivers whom the family have grown to know and trust are left behind. An uncomfortable realization that there is to be no cure is reinforced emphatically by the other children and their technologic chains. There are concerns about finances. Helping the parents through this period and eventually developing a strong alliance with them is part of our goal. Our efforts are directed towards: 1) a mutual trust established through clear communication, consistency, honesty, and provision of a nonthreatening environment; 2) incorporation of the family into the care plan. Short-and long-term goals are reviewed, explained, discussed, and adjusted to meet the needs of the parents; 3) establishing the parents as effective, confident caregivers and advocates of their child; 4) when appropriate, transfer of the child's care to a home environment.

Parent-infant bonding is essential. What we often see are parents who are afraid to touch or hold their child. We intervene and set the example by touching the child, stroking the child, and encouraging them to do so. We appreciate that the parents have gone through the first stage of bonding when they feel comfortable enough to go to the crib, drop the side, and independently gain access to the child. Then we move on to encouraging those aspects of care which represent caretaking: providing clothes, activity of daily living, caretaking tasks, comforting, and meeting special health needs.

We then encourage and reinforce the parents' identifying the child as their own and as their responsibility. This process might be called desensitization, or bonding, or behavior modification. It might also be looked at simply as education with interim goals and the need to meet certain criteria before moving from one level of education to another. Indeed, these families do move through basic child care, sensory motor stimulation, nutritional care, daily respiratory care, and equipment management.

Invariably, the parents reach a point where they feel that they are just as capable of taking care of their child as the doctors and nurses. While they were evolving to that point, they saw other children go home with supplemental oxygen or tracheostomy, or mechanical ventilation. They see children and families coming and going for out-patient visits and sometimes just for socializing. Eventually their sense of self-confidence and peer pressure brings them to ask the question, "Can we take our child home?" The answer is, "That's a substantial commitment—let's sit down together and

review it and see if it's the best thing to do." We do that, and invariably for the parent who asked this question, it is the best thing to do.

We examine various aspects to determine whether it's appropriate for the child to go home. Inability to wean is considered. This might just as well be inability to be independent, or hyperalimentation, or inability to be independent of intravenous antibiotics, or inability to be independent of dialysis. We look for patient stability. We look for an involved family unit. We look for an appropriate home environment. In our experience, this environment might be on the main line, a trailer park, a farm, or an apartment. Generally, the physical plant that is appropriate for the family is acceptable for the ventilator-dependent child. An important consideration relates to the electric capacity which must be adequate so that the ventilator and suction will work if someone decides to use the toaster. We look for two skilled caregivers. For this we use a checklist with some 30 differents points of skill and knowledge that the family needs. We look to see if service and supplies are readily available in their community. These needs have not been problem areas in Pennsylvania or New Jersey. Finally we look for money.

Financing Home Care

Consider the family who has a major medical coverage with INA, Aetna, or Prudential. The policy rarely pays for extended nursing care in the home. However, we can call them and explain that the child has respiratory failure which requires hospitalization. In addition, we point out that the child's family has major medical coverage so that the annual cash flow is substantial. We then outline to the company how they can reduce their annual cash flow by about 75 percent. Happily, we have not been disappointed. In all cases they have elected to capitalize the equipment needs for home care and to underwrite nursing for these children.

We had another child who was insured with the Carpenter's Union. His benefits did not extend to home care. We explained this to the regional representatives who referred us to the board of directors. We sat before the board of directors and explained the child's needs and the cash flow problems. The board of directors felt that they could not make an exception for any one child, so they voted to change the policy and make it retroactive so that this particular child and all others could be covered.

Contrast that with this response that I received from a Health Maintenance Organization when I asked for financial help to undewrite home care. "The child is already through our $100,000 corridor and now she is covered by our re-insurance carrier. We wouldn't dare send her home and risk having her re-admitted. If we did that, we would have to pick up the corridor again. Keep her in the hospital. It's paid for." The question of what was best for the child wasn't to be discussed, but we did discuss it further with the involved parties and were eventually able to effect a solution which allowed for underwriting of home care.

The response from Blue Cross is variable. In Pennsylvania, the important precedents have been set and currently they will pay for the equipment and partial nursing support.

CHAMPUS has evolved, and an important precedent has been set. Recall the child with the total thoracic ectopic cordis. More recently, an Air Force dependent was discharged home with mechanical ventilation. All equip-

ment, including backup equipment, was funded through CHAMPUS, as was sufficient nursing to allow parents respite and the opportunity to keep their jobs. It wasn't easy for the parents—they worked alternating shifts—but they did have their son home with them after 3 years of hospitalization. Within 4 months the child was weaned, and 3 months thereafter he was decannulated.

Until recently we couldn't budge the medical assistance system. They would pay hospital costs, often up to $210,000–220,000 a year per patient, but they would not provide nursing support for care at home. However, important precedents are now being set. Secretary of Health and Human Services Richard Schweiker has set up a Federal review board so that these cases can receive individual review and he recently allowed for waiver of rules so that Medicaid money can be used for at-home care. Just four weeks ago, Governor Kean of New Jersey came to The Children's Hospital of Philadelphia to send off the first such patient to New Jersey.

Several years ago, the Commonwealth of Pennsylvania, through the leadership of Representative Mary Ann Arty, and Governor and Mrs. Thornburgh, made monies available for a pilot program for home care of ventilator-dependent children. The program provides for disbursement of Commonwealth of Pennsylvania Department of Health and Welfare funds to meet the legislative intent of Appropriation Act 17A of 1980. Through the terms of this Act the Commonwealth contracted with a private corporation to develop a program to allocate State funds for services, equipment, and supplies for care at home of ventilator-dependent children. This public-private experiment has been cost-effective, has facilitated hospital discharge for ventilator-dependent children, and has increased the availability of community support services.

The program now supports 25 children and their families in their homes. However, there are over 200 more patients in acute care environments in Pennsylvania who might benefit from this kind of program—with enormous savings to the third-party payment system.

Providing home care for ventilator-dependent children does not necessarily require more dollars. Indeed, we can extend our resources by defining less expensive and equally effective alternatives to hospital care and by redesigning the reimbursement process to meet patient needs to allow for payment of the less expensive alternatives. In the model problem of the ventilator-dependent child, care can be better at home. There are clearly fewer infections, development progresses more rapidly, and where weaning is possible, it occurs more rapidly. In addition, care is less costly for this group at home.

Our system of health care delivery has effected a growth in the numbers of disabled infants, children, and adults. Among these disabled, ventilator-dependent children have been denied access to reasonable alternatives of care because of misperceptions about the complexities of their needs and because the system has not adjusted to meet the needs of that which it has produced.

Our experience in Pennsylvania indicates that care at home in particular is a reasonable alternative for ventilator-dependent children. This alternative has not been available to all families who might benefit from it. We need to learn how to make it uniformly available and of high quality.

THE NEW YORK EXPERIENCE

Mathew H. M. Lee, M.D.

Goldwater Memorial Hospital is a 912-bed facility specializing in long-term rehabilitation and treatment of chronic illness. As part of the Health and Hospitals Corporation of the City of New York, the hospital maintains a longstanding affiliation with New York University Medical Center. The long-term rehabilitation effort focuses on the team approach to patient care along with the individual's discharge potential; that is, discharge of each patient as a viable, productive, and self-supporting member of society, living outside of the institution in the general community.

We have recently conducted a study to explore the independent living problems of the severely handicapped respiratory patient as related to his personal adjustment, health care, and economic survival.* The objectives of the study were as follows:

1. To assess medical and social resources available to the severely disabled respiratory patient living independently in the community.
2. To evaluate the cost effectiveness of these resources.
3. To develop a comprehensive rehabilitation service plan which includes medical treatment, public health nursing, pulmonary testing on a routine basis, and maintenance of life-support equipment and motorized wheelchairs.
4. To assess the need for other types of clinical care including occupational therapy, physical therapy, speech and audiology, psychological therapy, and vocational counseling.
5. To assess vocational potentials and training of these patients as a function of their medical condition and functional mobility.

The following table demonstrates that home care of the ventilator-dependent child should be thought of as a continuing process which can proceed into adulthood. One-third of the patients studied have lived at home for more than 10 years.

YEARS LIVING IN COMMUNITY AFTER ONSET/DIAGNOSIS

	N	*%*
Less than 2 years	7	8.1
2 - 5 years	30	34.9
5 - 10 years	19	22.1
10 - 15 years	10	11.6
Greater than 15 years	18	20.9
N/A	2	2.4
	86	100.0

The next table shows distribution of the vital capacities of the patients in our survey.

PERCENT VITAL CAPACITY

	N	%
0 - 10%	12	14.0
10 - 20%	18	20.9
20 - 30%	14	16.3
30 - 40%	10	11.6
40 - 50%	9	10.5
Over 50%	22	26.7
	85	100.0

You will note that some people in the study (34.9%) have vital capacities reduced below 20% of their normal predicted volumes, and that a total of 63 people (73.2%) were below 50% of their predicted vital capacity. In past years, people with this degree of pulmonary compromise died from carbon dioxide retention and subsequent cardiopulmonary arrest, usually precipitated by pneumonia or other respiratory infections.

The twenty-two (26.7%) patients falling into the over 50% vital capacity category may not experience respiratory distress under usual circumstances. However, during a cold or intercurrent infection, they require ventilatory support to exercise their lungs and help mobilize secretions. Often they cannot expel thick secretions and require medical treatment with antibiotics and expectorants, along with judicious physical therapy of the chest (pulmonary toilet) during an illness. All of these clients are at risk when faced with a respiratory infection and require prompt and experienced medical intervention.

Ideally, professional rehabilitation services allow the patient to move toward independence at his own rate. In this ideal, support and guidance are fostered, while the individual encounters and overcomes the problems of a new lifestyle. This support can be diminished progressively as the individual reassumes the ability to make a choice and carry out his needs. However, there is a definite existential difference between these elements of human potential and actual access to knowledgeable medical care and supportive services. These services are the *sine qua non* for conditions favorable to community life and subsequent employment.

During the course of this study, lengthy discussions with patients strongly suggested that they do not want to exhaust the financial supports offered by society. These individuals do not consciously choose physical immobility and dependency. They desire to regain control of their own lives. Urban planners and health planners alike are aware of the existence of disabled people, and gains have been made in many areas. Patients acknowledge reforms, yet the fact remains that the day-to-day experiences of living in a wheelchair are still frustrating. Simple survival in a world not ready to receive quadriplegics is a continuing struggle.

In this regard, we at Goldwater Memorial Hospital are planning to meet the medical health maintenance needs of patients by establishing an Independent Living Center. Goldwater Memorial Hospital's specialized and unique respiratory care services are available currently to hospital inpatients and a large number of community-based residents. The Center will assist the patient in maintaining his community residence by the provision of individually selected service support.

Observation of the lifestyles of members of the severely handicapped community serve to expand our conception of human potential. Comprehensive rehabilitation efforts, along with re-education, allow us to recast an image of an immobile, dependent human being, to that of an active, autonomous, reflective being, despite severe physical and functional limitations. Medical and health practitioners must give increased attention to implementing the consistent support needed to help the patient achieve this goal. When appropriate support is available, the patient has the capacity and the need to assume responsibility for his own existence. In many cases medical and institutional expenses have been reduced following the comprehensive rehabilitation and educational training of motivated patients. The cost effective nature of rehabilitation is not to be underestimated.

*This study was supported by a grant from the New York State Office of Vocational Rehabilitation. Copies of the report of this study can be obtained by contacting our hospital.

THE ILLINOIS PLAN

I. Program Perspective

Allen I. Goldberg, M.D.

The Illinois program for the home and community care of ventilator-dependent children will be presented from three perspectives. I will first describe the advantages which we have found in moving the children from acute bed treatment at Children's Memorial Hospital to the far less expensive and more satisfying care at home. I will also define some of the problems the program has encountered and ways in which we have attempted to cope. Then Mr. Eugene Bilotti, Administrator of the Programs, will describe how services are delivered and reimbursed. Finally, Dr. Arthur Kohrman will discuss our efforts at regionalization.

Our experience at Children's Memorial has had and continues to have its difficult periods. Perseverance by our staff and by the families of the children in the demonstration project has resulted in satisfaction in many ways for those who have been transferred successfully to home care.

First, the program saves money. The cost of hospital acute or intermediate care has risen by 84 percent in the past five years, from about $400 per day to about $1000 per day for acute care and to about $750 per day for intermediate care. The cost for care at home has remained at about $250 per day initially after transfer and in time drops to under $200 per day.

Examples of the above follow:

I

Patient D. W.—Age at discharge—3 years 4 months — Discharge Date: 9/10/79

Condition: Partially ventilator-dependent

- 1 hour "free time"
- 35% O_2 support

Hospital Care Costs *March 1, 1979 - August 31, 1979* 184 days (6 months)		*Home Care Costs* *January 1, 1981 - June 30, 1981* 181 days (6 months)	
Intensive Care	$ 67,550	Nursing	$ 31,680
Pharmacy	990	Central Medical Supply	460
Radiology	260	Life Care	1,560
Laboratory	1,760	CMH	2,930
Central Supply	1,490	AAMED	4,390
Respiratory Therapy	65,190	Barton Research	870
Physical Therapy	2,450	Marie Lynch	180
Cardiology	30	Total	$ 42,070
Take home drugs	20		
Non-covered charges	260		
Total	$140,000		

$\frac{\$140,000}{6 \text{ months}} = \$23,330/\text{month}$

$\frac{\$140,000}{184 \text{ days}} = \$760/\text{day}$

$\frac{\$ 42,070}{6 \text{ months}} = \$7,010/\text{month}$

$\frac{\$42,070}{184 \text{ days}} = \$230/\text{day}$

II

Patient H. S.—Age at discharge—1 year Discharge Date: 6/1/81

Condition: Totally ventilator-dependent
- ventilator at night
- diaphragmatic pacers during day
- no oxygen required

Hospital vs. Home Care Costs
6 Month Cost Comparison
Private Insurance—Midwest

Hospital Costs 1981	*Home Care Costs 1981*	
$189,250/182 days	$45,630/184 days	Total
$ 1,040	$ 250	per day
$ 31,540	$ 7,610	per month

76% Decrease

Secondly, our program has demonstrated recognizable values in having these children grow up in a more normal and human environment. Their personalities broaden; they interact with their parents and siblings; they attend school; and they can participate in their religion. Some improve to the point of no longer requiring support.

By 1980, it had become apparent that the application of advanced medical knowledge and sophisticated technology by organized teams of health care professionals was saving an ever-enlarging number of disable children needing a variety of solutions and services not readily available. Demonstration projects of home care were not enough. Some children needed other options for social, educational, and future vocational reasons. Study led to the calling of a Conference on the Chicago Program, in October, 1981, to understand better and to define the present situation and to plan for the future. At the Conference, we asked, "Whatever Happened to the Polio Patients?"[1]

Why polio? There are three reasons:

- First, the modern medical disciplines of critical care and rehabilitation medicine have evolved from the organizational and technological advances made in response to the worldwide crisis created by polio.
- Second, the resulting excellent health care has created a new and enlarging population of survivors of many diseases and conditions who depend upon life-supportive technology.
- Finally, these new survivors face many problems and have a diversity of unmet needs similar to those of the polio patient of the 1950s.

What is the situation *now* regarding the ventilator-dependent child?

The proceedings of the Conference are available from the Rehabilitation Institute of Chicago, Dr. Don Olson, Director, Education and Training, Northwestern University Medical School, Rehabilitation Institute of Chicago, 345 E. Superior St., Chicago, IL 60611. Tel: (312) 649-6179 or Eli Henig, Rehabilitation Institute of Chicago. Tel: (312) 649-6190.

The Health-Care Perspective

Regional acute care centers utilize valuable technological and professional resources for months and even years at an enormous cost. Facing decreased Federal, State, and insurance cost-reimbursement, they must limit their facilities' capacity to serve acute care patients.

Regional rehabilitation and long-term care institutions have available or acceptable resources to meet many of the needs of these children on ventilators. They could provide cost-effective, appropriate care if they had adequate preparation to do so. At present, these institutions do *not* accept these children. Such institutions also face economic constraints and need new directions for their missions.

The Consumer Perspective

The needs of a ventilator-dependent child disrupt family unity and tax all the strengths of a marriage. Both *health care consumer* (patient and family) and the *physician in the community* face inappropriate utilization of institutional resources because of a lack of information, education, and/or an organizational approach. Consumers have the potential to help find the solutions to these problems if given the opportunity. Instead, the excessive costs of acute-care domiciling are indirectly added to everyone's burden as taxes and insurance premium costs.

The Organizational Perspective

Health Care Service Providers are finding an increased demand for their services and products, but mechanisms for reimbursement do not meet the diversity of services they can provide and the cash-flow they require for operation. They seek guidelines for meeting a standard of care and mechanisms of coordination and communication with health care facilities, third-party payment agencies, and insurance companies.

Public and Private Funding Sources recognize that alternatives to institutionalization can save money on a case-by-case basis. There is some uncertainty about the *total* cost-savings once a more workable and universal system of reimbursement is in place. In some cases, fragmented funding for human services can be combined for a *total* cost-savings. Funding sources recognize that there presently exists no standard of home care, no operating procedure, and no established case management/case monitoring system. Furthermore, there is concern about the appropriateness of treatment by medical providers. For example, the Blue Cross Association has recently enacted "Medical Necessity Programs," such as one for Respiratory Care, which is a responsible, well-planned approach to reduce unnecessary costs for non-essential services.

Voluntary Service Organization and Non-Profit Health Care Agencies have excessive demands upon limited resources. They need education and information to adapt to meeting new needs and guidelines to determine services.

Other Organizational Possiblilities: Many organizations that care about people (religious service organizations, and community-based voluntary groups such as Rotary, Lions, Kiwanis, Elks, and Shriners) have "grass-root" resources. Many search for new directions. They can help provide local support for intact families or alternatives to the family. Today excessive health care costs have nearly exceeded our ability to pay. Unless we design operational systems and reimbursement mechanisms, we face the danger of curtailment of services and a resultant decline in the quality of life, or even survival, for some disabled people. Our past demonstrations and those of others abroad have proven that a higher quality of care can be more appropriately given with the family or in the community at enormous cost-saving. We can provide better care for less money. The solution of the problems of the ventilator-dependent child will have far reaching and universal benefits because of appropriate application to the many other complex health care and societal problems we face today.

II. Home Health Care—Case Management Approach

Eugene E. Bilotti, Administrator/SSI-Disabled Children's Program

Years of singular growth and development had left health programming and social service agencies where it was hard to conceive of a plan that would place a severely medically involved youngster in his or her own home with $16,000 worth of sophisticated medical equipment and around-the-clock nursing services. Nevertheless, this is what the ventilator-dependent children brought to the scene. The Illinois Department of Public Aid had no official policy concerning such children. With each involvement, it had to establish an exceptional policy waiver. The Federal government was beginning to address the issue by a task force established to study and subsequently to make recommendations for the care of these children. Exceptions were also required by Crippled Children's programs as well as insurance carriers.

The need for such a plan was obvious to all concerned parties. The most notable was that *the child would be placed in the loving environment of his or her own home.* A second was that there would be an *immediate cost reduction of approximately two-thirds of the cost for institutional care.* The limitations of such programs were also obvious in the medical/safety and social areas. When planning for these children to go into their own homes, we needed to be aware that emergency medical support would be absent. Obviously, careful detailed planning was necessary in order to not threaten the child's life and/or safety. All the assets and liabilities being weighed, it was decided that we would attempt to place a child in his own home. We developed a case management approach. It should also be noted that *other children with similar needs, although perhaps not ventilator-dependent, would need to follow the same type of case mangement approach.*

The following is the Illinois approach to home placement:

1. **Medical Plan**
   Our Illinois approach begins with a very thorough medical protocol. This plan is detailed to the point of specifying every piece of equipment and a careful list of supplies. It also indicates who is to order the equipment, the designation of the primary physician, provisions for backup emergency care, a designated hospital to assume emergency responsibilities within the geographic area, an available respiratory therapist to monitor the program, and a careful description of other professionals needed.

2. **Case Management Plan**
   A home case management plan is developed that clearly details and limits the persons and agencies involved.

3. **Nursing Services Plan**
   This plan includes a program for procuring the nurses, a plan for training and for determining an hourly rate of reimbursement. The nursing plan also details a projection aimed at reducing the number of nursing service hours from 24 to 16 hours a day and then to 8 hours a day, with the hope that the family will eventually be able to function without regular nursing service.

4. **Financial Planning**
   An exact financial plan is essential. Without a means of paying for the total program, all programming would abruptly end. The role of involved and legally responsible insurance carriers is determined. A plan is developed with the medical assistance unit of the Department of Public Aid defining their role and the amount of responsibility they will assume. The plan also includes a projection to reduce costs within six months to a year.

5. **Family/Home Care Plan**
   The suitability of the family situation needs exploration. It is generally anticipated that a professional social worker will be needed at this point, for the family needs to understand the likely impact of this placement. The physical arrangements of the home need evaluation. There should be a suitable room for the child with proper heat, light, space, and an alternate power source.

6. **Community Involvement Plan**
   The overall plan details the involvement of the community. The local fire department, police department, and highway department need to be aware of the presence of a ventilator-dependent child. Arrangements also are made for local emergency medical services such as a local doctor, preferably a pediatrician, to tend to this child in emergency situations.

7. **Equipment Plan**
   An equipment list includes such items as backup suppliers, local pharmacy suppliers or providers, and ready information dealing with service or repair of the equipment. It is anticipated that backup equipment will be on hand.

8. **Discharge Plan**
   There is a detailed discharge plan that includes emergency alternative plans, such as the local hospital that would tend to the child in an emergency and a contingency plan for return to the hospital from which the child was discharged.

Although we feel that overall case management system in Illinois is not in its final form, we do feel that we have made strides in systematizing our approach and in getting these children safely and successfully into their own homes.

III. The Consortium

Arthur Kohrman, M.D.

The needs of the child with long-term dependence on high technology for continuing care must be met at several levels. The most effective means of providing services will be the bringing together of the various institutions and services within a given region. We are forming such a consortium in the Greater Chicago area with the support of the funding agencies of the State of Illinois, particularly the Division of Services for Crippled Children and the Department of Public Aid.

Our initial efforts are focused on children with long-term or permanent needs for mechanical ventilation. We have begun a network of services and care which will ensure continuity, quality, and the greatest hope of the appropriate placement. It is anticipated that regional tertiary acute-care hospitals will continue to receive patients needing meticulous attention to airway, pulmonary, and cardiovascular care. It is hoped that a large percentage of children with long-term or permanent ventilatory care needs will ultimately be placed in home settings. Some can be discharged directly home from acute care units, but most will require intermediate-level facilities while caretakers in the alternative setting can be trained. For many, poverty and unstable homes make it impossible to construct adequate settings at home. We hope to train foster parents and set up new "families" for these children.

An institutional consortium approach is now being organized consisting of Children's Memorial Hospital (the largest children's hospital in the region), Wyler Children's Hospital (the acute care hospital of the University of Chicago, Department of Pediatrics), Michael Reese Hospital (also University of Chicago, Department of Pediatrics) and LaRabida Children's

Hospital and Research Center (the chronic care hospital of the University of Chicago, Department of Pediatrics). Currently, home discharge teams (at Children's Memorial, Wylers, and Michael Reese) are preparing protocols to arrange for progressive preparation for discharge of chronic ventilator-dependent children, either to LaRabida or directly to home or other domiciliary setting now available in the Chicago area. LaRabida is planning to serve as an intermediate care setting. The capabilities of LaRabida are rapidly being enlarged to handle ventilator-dependent patients. It is also anticipated that LaRabida Children's Hospital and Research Center will develop significant programs of research and education around the very complex set of problems which these children present.

It is clear that the maintenance of such a network is going to require extensive ability to monitor patient flow and status, to produce and evaluate educational materials, programs, and protocols, and to bring together funding guarantors to establish the most effective and comprehensive payment programs. Thus, the developing consortium, in addition to seeking consultation for preparing each of the member institutions to provide a uniform standard of care and coordination of services, is also seeking assistance from an organization,[2] external to the institutional members which will coordinate personnel, parent, and patient education; act as an information clearinghouse; maintain a flow of patient records and appropriate statistics; and act as the center for the coordination of payment sources.

[2]*Care for Life* is a not-for-profit organization providing services of documentation, education, and demonstration designed to meet these objectives and others that follow (documentation center, community-based options for the disabled).

THE CHILD AT HOME

Mrs. Bette Wartenberg

My name is Bette Wartenberg. I am Donnie's mother. I am here to present the parents' view. I will describe the implications of a child's chronic illness on the family, the financial issues, and the complex problems encountered by my family. In addition I will compare experiences reported by other parents in our parents' group.

Donnie, my sixth child, was born with defects that involved the left side of his body including his left lung, which later on had to be removed. At the time of his birth we were told that Donnie had to undergo immediate surgery because of what is called an omphalocele, which means that his navel and stomach had evolved outside of his abdomen. Within 4 hours of birth he was transported from Joliet Hospital to Children's Memorial Hospital in Chicago, where the first stage of surgery was performed immediately.

For us as parents, the first shock in the delivery room was knowing that our child had multiple birth defects. We were overpowered by fear of losing our child. Later, the fear was intensified by observing our child in the ICU, when his heart stopped 18 times and he had to be resuscitated. Only because of the prompt response from health care personnel, Donnie survived all this without brain damage.

During his first 3 years in an acute intensive care unit, Donnie underwent a total of 20 operations. Most of the time he was breathing with the help of a machine—a ventilator—receiving numerous intravenous infusions and treatments while we were watching as helpless by-standers. We often did not understand what was done, the reason why, and we had no knowledge of the alternatives.

Our main social contacts were other parents of critically ill children in the ICU waiting area who, over a period of months, became like close friends to us. Some were the unlucky ones; their children died. We grieved with them, always thinking that we could be next. After years of this, we shut ourselves off and avoided contacts with those parents—even to the point of being abrupt.

We did not receive professional help to deal with the psychological stress we were under. My husband dealt with it by talking constantly about it, while I tried not to think or talk about it, which caused great problems between us. We lost a lot of our friends. They did not know what to say, so it was easier for them not to see us. Besides, we were no fun to be with, because we were constantly talking about our problem.

During his years in the ICU, attempts were made to wean Donnie off the ventilator. A pediatrician forcefully suggested that we take Donnie home, that is, to die. We took Donnie home. He had a tracheostomy; that is, a hole in his trachea. He was breathing poorly by himself; we thought he would not live much longer. We were not prepared to properly take care of him at home. We did not even know how to regulate the oxygen flow. He was home for two months, only to return to the Children's Memorial ICU because of pneumonia and failure to thrive. By then, we had lived through two months of a nightmare with no help, no medical caregivers, no sleep—only worry. We were exhausted and burned out.

We shared this experience years later with other parents who at the time were sent home unprepared, with a child who could not breathe by himself without a mechanical aid. This couple had ventilated their child by hand 24 hours a day, taking turns day and night for months, until the decision was made that the child needed a mechanical ventilator at home.

Our home is in Joliet, Illinois, 60 miles from Children's Memorial Hospital in Chicago. Rather than spending 2 to 4 hours on the road a day, we chose to move into the waiting rooms at Children's Memorial Hospital, where we lived for over a year. We slept on the couch, showered in the basement locker rooms, ate hospital food, and paid parking fees. Our 5 children, ranging in age from 17 to 12 years, were left unattended most of the time. They learned to take care of themselves. After about a year, my husband and I decided that one of us had to stay at home in Joliet because our other children were beginning to feel the effects of our absence. I went to Joliet, returning to the hospital occasionally, and my husband stayed with Donnie. Consequently, he lost his business and to live we had to borrow money from family members. Besides dealing with this stress, there was no money or time to go on vacations with the other children. We haven't had a family vacation for 10 years!

Our insurance covered $100,000 of Donnie's care. After a few months, we were told to apply for financial assistance to Illinois Public Aid and the Division of Services for Crippled Children. Children's Memorial Hospital was very helpful in helping us apply. We qualified because Donnie was born with multiple deformities.

Why is it much easier to get aid if a child is born with defects than if some illness or accident causes defects at a later date? Others in our parent-group had children who had problems getting financial help. One parent was called into the hospital billing department and was presented with an astronomical hospital bill and was asked "How are you going to pay for this?" Some parents were advised to go on unemployment, go on public aid, and even get a divorce.

After spending the better part of 3½ years in an Acute ICU, Donnie was transferred into an intermediate care unit for his long-term care. Repeated attempts to wean him from his breathing machine caused him to be lethargic, puffy, and turn blue. He ceased to grow. The only time he was well was when he was on his ventilator. Then he became a very active, happy child. His many arrests had apparently not damaged his brain. He had become a very precocious child, even inventing his own sign language!

Even though we were at his bedside as much as possible, many of the functions of a parent were taken over by nurses and other health caretakers. Correcting bad behavior or eating habits is hard to accomplish outside of a family setting.

Since Donnie was confined to this unit by being on the ventilator, he lacked opportunity for an education appropriate for a 4 year old. At this time he got ½ hour of tutoring a day. Children's Memorial Hospital, being an acute care hospital, was unable to provide additional education for a chronically disabled child.

Then in 1978 a new idea was presented to us by a new staff physician. Give Donnie optimal ventilation so he can grow. Prepare him to go home safely with his ventilator. With our memories of the past experience, the

idea horrified us. But after meeting with qualified medical personnel, we were assured that we would be trained and would have medical help to support us. Donnie needed to go home in order not to become socially handicapped. Once while I was talking to him on the phone, I told him I was sitting at the kitchen table. After he hung up, he asked his nurse "What is a kitchen table?" My other children were delighted when we told them that Donnie could come home, and they were anxiously awaiting his arrival.

In 1978 no money was allocated by Federal or State law to care for ventilator-dependent children at home. The State knew how to pay the high costs of intensive care but had no experience in providing funding for less expensive care at home. A long period of negotiation took place. The State officials finally found the solution to pay 100% for 2/3 less expensive medical care at home. We were luckier than others in the parents' group who were faced with the spend-down money (money to be paid according to income by the family to the State).

Some parents in our group had private insurance. The insurance company refused to change their reimbursement policy for home care. The insurance company was willing to pay everything in hospital, but refused payment for home care. As a result, the insurance company rapidly spent the $500,000 in the hospital. This money could have lasted for years at home. They had no incentive to change. Therefore, public funds were needed sooner, because the private insurance money was gone so quickly while the patient remained in the ICU. So the burden was tranferred to the State and ultimately to the taxpayer.

Transition

It took nine months from the time the decision was made to send Donnie home before it really happened. During that time we built a specially adapted addition to our house. Regular meetings with the health care team were held. These meetings clearly defined goals acceptable to all, and provided clear objectives and specific plans for action. Each team member had accountability. The home discharge team included the dedicated clinical staff who had cared for Donnie over the years. The coordinator was his nurse; the educator was his respiratory therapist. Both were caregivers who had received him in the ICU shortly after his birth. The team also involved physical and child-life therapists, special service staff, social workers, etc. Initially, several members had to overcome their own fear and negative thinking, but the more educated they became, the more they were able to overcome this barrier.

My husband and I were trained to handle Donnie's ventilator equipment by both classroom teaching and "hands-on" experience. We passed a test and were certified. Nurses we recruited, selected, and hired to provide 24-hour home care were trained with us at the hospital, in the classroom, and at the bedside. Community support services, including a primary physician and emergency room staff in Joliet, were well-informed about their responsibility prior to their consent. Nursing, physical therapy, and respiratory therapy plans and exact procedures were clearly written, and local suppliers of medical equipment were found, motivated, and well-

prepared. Funding was finally approved because of highly motivated and responsible actions of the leaders and staff of the Division of Services for Crippled Children, the Illinois Department of Public Health and SSI Disabled Children's Program.

The team work of all these individuals made the home program a reality.

Home

On September 10, 1979, our son came home to stay. It has been a difficult task. We are dealing with a lack of privacy, the ventilator breaking down, lack of service for equipment, and difficulties in getting medical supplies.

However, the benefits of having Donnie at home far outweigh the difficulties.

We are now a normal family, maybe different in some ways, but we are all together, sharing all the experiences of life. We no longer divide our time among our children. Donnie's health has improved; he has grown several inches. His oxygen need has decreased. His social life is no longer limited to the ICU where he never knew the difference between day and night. He is now getting an education, doing average-to-above-average work. He no longer has to regard cardiac arrests in the bed next to him as his only occasion for "social-get-together." Instead he goes to weddings; he was a ring bearer at his brother's wedding where he never missed a dance. Donnie is a joy to be with. He loves his religion. He celebrated his Holy Communion last month. He tolerates being off the ventilator with oxygen longer. He races his race car (recently he placed first in competition), climbs trees, and he even fell and broke his arm at a birthday party. Donnie worries right now whether he will get married one day. He is concerned that it is not much fun to go trick or treating, because no matter how he dresses up, everybody recognizes him by his tracheostomy. His nightly prayer includes: "Dear God, if you are listening, please get rid of my trach so I can play football."

We know we can go back to Children's Memorial Hospital any time we have any problems with Donnie. He will be well taken care of by loving people who know him and care for him and us.

We are deeply grateful to the staff of Children's Memorial Hospital. They never gave up hope. And thank God nobody pulled the plug in the ICU. Thank you.

WORK GROUP RECOMMENDATIONS

INTRODUCTION TO WORK GROUPS

When The Voices of Children Are Heard On The Green
And Laughter Is Heard On The Hill,
My Heart Is At Rest Within My Breast
And Everything Else Is Still.

William Blake

All of those participating in the Workshop have made a commitment to improving the quality of life for children with handicapping conditions and their families. In sharing this common goal, they shared a common struggle—a struggle that is bounded by our limits in knowledge, technology, and resources. It is a struggle that taps boundless human compassion and tests every bit of creativity. The task of the work groups was to challenge each limit and to invoke all of our talents to solve the urgent problem of extending humanistic and comprehensive care to *all* handicapped children and their families.

They were a diverse group with a diverse perspective: parents, professionals from many disciplines, public and private service providers, financers, and policymakers. The interaction of their combined perspectives has the potential for generating unique strategies and solutions that can serve to shape a nationwide effort. As a case example, the ventilator-dependent children provide a rich opportunity to go forward with innovative strategies that can affect all handicapped children and their families.

For a day and a half, ten working groups examined two key areas of concern: organizational and financial considerations. In each area a broad range of issues was addressed by the groups. Organizational considerations included the scope of approach to delivery of essential services, institutional roles and limitations, and public and private organizational roles and limitations. The groups examined the means of overcoming deterrents to care in the community, of promoting family autonomy, of setting standards for quality assurance, and of defining educational and research needs.

Financial considerations included approaches to reimbursement for ventilator-dependent children, reimbursement for community-based care and for tertiary and intermediate institutional care, cash-flow dynamics, multiple sources of funding for comprehensive care, and research in financing services.

Each group also examined existing processes and mechanisms—their advantages and limitations, the deterrents to improvement, and strategies for the evolution of family and community management of care for these children.

The groups presented their recommendations to Drs. MacQueen and Kettrick who synthesized these and identified common themes to present to the Surgeon General at the close of this Workshop.

RECOMMENDATIONS

The participants in the workshops were assigned to ten working groups of approximately fifteen persons each. Each group was assigned specific, related sets of issues to examine in depth. The groups were to define existing processes and mechanisms, their advantages and limitations, and the deterrents to improvement. They were also asked to develop strategies for the evolution of family and community management of the care of ventilator-dependent children.

The work groups looked at what was working in the system, defined numerous needs and problems and deterrents, and suggested strategies for improvement. The diversity of perspectives, the flow of ideas, and various tangents of the interactions present in the work groups cannot be covered adequately in this document, but some of the more pressing programs, needs, and strategies are distilled and categorized here. For the purpose of providing a framework for presentation, ten categories have been defined. The deliberations are reported under these headings:

1. Data
2. Institutional Matters
3. Family Considerations
4. Regionalization
5. Standards for Quality Assurance
6. Abuse and Overutilization
7. Professional Education
8. Family Education and Public Awareness
9. Research
10. Finance and Reimbursement

Most of the topics cut across the lines into more than one of the above categories, so that reference may have to be made to more than one section in order to find all the suggested strategies for any given topic.

CATEGORY 1: DATA

There is a need for accumulation, dissemination, and utilization of data.

DEFINITION OF THE ISSUE AND ITS EFFECTS:

If we had adequate epidemologic and demographic information we would be better prepared to develop programs for the care of ventilator-dependent children.

On a case-by-case basis we have figures which demonstrate significant dollar savings for home or community care, when contrasted with in-hospital tertiary care, but these numbers need to be refined and monitored. Because such a limited number of programs for home care are now functioning, we have not been able to accumulate data for the "ripple" which the move of large numbers of ventilator-dependent children from tertiary units might have on the financial structure of the medical system as a whole.

SUGGESTED STRATEGIES

1. Convene a working group to define, within a time frame, the needed information. The group should have representation of economists, statisticians, and health care providers.
2. Implement a continuing data collection and information system.
3 Disseminate the collected information to organizations and reimbursing agencies which can apply it to improving care and financing.
4. Conduct epidemological studies to follow the natural history of diseases which leave children ventilator-dependent.
5. Conduct a survey to determine the current patient care and reimbursement status in each of the States.
6. Conduct cost-effectiveness studies to assess the quality and costs of care in various settings.

CATEGORY 2: INSTITUTIONAL MATTERS

Multi-tiered institutional models should be adopted to provide care for ventilator-dependent children. There are 3 major groups: acute care facilities, transitional units, and non-institutional alternatives.

DEFINITION OF THE ISSUE AND ITS EFFECT

Acute care facilities should be reserved for care from the onset of medical crisis until stabilization. Transfer should then be effected to a transition, intermediate, or rehabilitation unit to prepare for long-term placement. Very few such transitional centers are now available for ventilator-dependent children. As a result, many children remain domiciled on expensive acute care units for far longer than is medically necessary. There have been serious barriers impeding transfer to home. There are almost no facilities for non-institutional living for those ventilator-dependent children for whom the biological home is not a viable alternative. Eventual placement in a home or home-like community-based living arrangement should be the goal for these children.

SUGGESTED STRATEGIES

1. Promote the development of transitional units, such as intermediate care centers or rehabilitation facilities that are pediatrically oriented.
2. Devise non-institutional, home-like living arrangements, such as group-living with shared services, foster homes, or subsidized adoption.
3. Work to remove the social and economic deterrents and barriers which prevent transfer to care at home.
4. Develop precise clinical and social criteria for transfer from one level of care to another.
5. Provide financial aid for tertiary units to allow them a major role in preparing patients and families for transition.

6. Provide for study of European programs of group living arrangements, which have been in successful operation for a number of years.
7. Study the effects on tertiary care financing after the long-term, ventilator-dependent children are moved from the tertiary beds.
8. Develop regional affiliation among institutions at the various levels. Provide financial incentives for those institutions participating in such a consortium.

CATEGORY 3: FAMILY CONSIDERATIONS

Starting at the earliest acute stages, the family must be encouraged to develop a strong involvement in the care of the ventilator-dependent child.

DEFINITION OF THE ISSUE AND ITS EFFECTS

The family of the ventilator-dependent child is often overwhelmed by the process of coping with the acute phase of the child's illness. The family unit is disrupted by the persistent encroachment of a new way of life for which there has been no preparation. Because of this devastating strangeness, the parents can easily come to rely on well-intentioned "professional parentalism" in their early decision making. As the patient stabilizes and becomes ready for an alternative to an acute unit, the family may have become too functionally paralyzed to participate in the process of considering such alternatives. After care at home has been inaugurated, continuing monitoring of family function must ensue.

SUGGESTED STRATEGIES

1. Encourage an early "bonding" process for the family to come into intimate physical contact with their child as soon as it is comfortable for them to do so.
2. Have the family assume as complete a responsibility and authority as possible from the earliest stage in the illness. This should be done in consultation with health and social service professionals.
3. Develop tools to assess the family's readiness for each transitional step.
4. Make parent counseling, mental health assistance, and specific therapy available where indicated.
5. Aid in formation of parent support groups and a parents' network for exchange of information and feelings.
6. Hospital staff education should be directed towards sharing responsibility with the parents in whatever way is compatible with the best medical care for the patient.
7. Provide for respite assistance for the family with a child at home.
8. Assist in structural changes in the home which make it easier for the ventilator-dependent child to lead as normal a life as possible.

9. Enhance payment of outstanding vouchers promptly, so that the family does not have the added burden of unpaid bills. A system should be inaugurated with third-party payers for advance allocation of reimbursement, so that the family can plan a reasonable financial budget with knowledge that monies are available when needed.

CATEGORY 4: REGIONALIZATION

All institutional, social, service, financial, and professional functions on behalf of the ventilator-dependent child should have regional coordination. A regional system can be developed at State level, across State lines, or intrastate, and with tertiary care center participation. The strongest emphasis should be on the community-based component of the regional system.

DEFINITION OF THE ISSUE AND ITS EFFECTS

The ventilator-dependent child at home needs essential services. At present, there is no coordination of delivery of these services, nor are there uniform methods of payment. There is, as one group put it, "no one in charge." A regional system for coordination of efforts can be developed within and among organizations which already exist, with each regional system responsible for defining and arranging each of its levels of service.

SUGGESTED STRATEGIES

1. Grants from the Federal level should be provided for pilot projects to delineate implementation issues in developing the structure of a new regional system for delivery of care.
2. Encourage communication among all providers of medical and nursing care, education, social services, recreation, transportation, psychosocial support, emergency services, equipment vendors, and respite assistance at the community level. This will enhance the coordination of community assets into the regional system and allow for easy entry of the patient into these facilities when transferred from hospital-based care.
3. Funding must be found to develop regional systems beyond the initial pilot projects. In time, the regional systems should become self-sustaining.
4. Public and private reimbursing agencies should participate in the development of the regional system. Such participation will allow for a more rapid solution of problems, with resultant savings. Those agencies which already exist for the family should be incorporated into the financial plan, whether Medicaid, Crippled Children's Services, Blue Cross/Blue Shield, or private insurers.
5. The coordinating center should accept responsibility for the patient's transition from one level of care to another.

6. The regional system should be developed with the objective of providing coordination of all community resources for the humane care of the child in the least restrictive environment compatible with medical status.

CATEGORY 5: STANDARDS FOR QUALITY ASSURANCE

Standards should be developed and quality assurance controls should be built into both institutional and community-based programs.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Standards should be written for the various levels of institutions and non-institution living arrangements, as they are being developed. Most importantly, standards should be set for the essential services and personnel which are necessary to support the ventilator-dependent child in the home. Quality controls cannot be instituted until minimal standards for services are established. The family of the patient will be able to make better decisions on contracting for services when they have standards to guide them.

SUGGESTED STRATEGIES

1. Professional organizations should be encouraged to work together to establish and promulgate needed standards of care.
2. Each system should provide a qualified home discharge team and should implement a post-discharge monitoring mechanism.
3. Standards should be established for medical criteria.

CATEGORY 6: ABUSE AND OVERUTILIZATION

There is a concern that abuse and inappropriate utilization will occur once systems are established for providing improved services for the ventilator-dependent child.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Technology may be used inappropriately, and there may be inappropriate use of personnel and equipment. Patient populations may enter into the system by way of unwarranted discharges to home care or because patients now on mostly self-sustained home care may apply for entry into the system.

SUGGESTED STRATEGIES

1. Establish safeguards against abuse and inappropriate utilization and provide for monitoring in the regional systems.
2. Establish standards and/or regulations to insure against cost inefficiency for all services provided.

3. Insure charges for community based services (i.e., group homes) are realistic and monitored to prevent abuse.
4. Set up central purchasing of equipment with loan or rental to the appropriate patient population.
5. Inaugurate monitored competitive bidding for equipment and provision of services.
6. Review past experiences of national programs requiring complex medical technology to identify problem areas and identify ways to avoid similar problems.

CATEGORY 7: PROFESSIONAL EDUCATION

Personnel delivering care at all levels must be adequately educated.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Professionals often find it difficult to work with the disabled because of attitudinal problems. They must develop sufficient background associated with the problems of disability and the needs of the extended families very early in the course of their training. Training of professional personnel must take place at all professional levels of pre-service and in-service education to allow updating and familiarity with new techniques at all levels. Medical, nursing, and allied health schools, schools of health administration and economics, business schools, and biomedical engineering centers should be involved.

Paraprofessional workers are an important part in the service delivery system and must similarly receive basic and appropriate continuing education.

SUGGESTED STRATEGIES

1. Incorporate education for care of the disabled into the curricula of higher learning.
2. Inaugurate and supervise an education program for health workers as a major function of the tertiary centers in the regional system.
3. Develop a national clearinghouse to allow for access to resource material.
4. Sponsor continuing education courses aimed at professional and paraprofessional personnel.

CATEGORY 8: FAMILY EDUCATION AND PUBLIC AWARENESS

The public remains unaware of many of the problems of the disabled. Families of ventilator-dependent children need ongoing educational support. Ventilator-dependent patients must be included in the educational mainstream when possible.

DEFINITION OF THE ISSUE AND ITS EFFECT

The public, and particularly the legislators, is unfamiliar with the needs of ventilator-dependent children. They are not aware of the beneficial effects on our social structure when the disabled are transferred to a more normal, productive life in our communities. Parents need continuing education from the earliest stage of the child's disability through the transition which results in the ventilator-dependent child being cared for at home. The child's education becomes one of the most essential services in planning for care at home.

SUGGESTED STRATEGIES

1. Groups should be formed to increase public awareness.
2. Government officials and third party payer executives at all levels should be made aware of the cost and humane benefits which result from a system of community care for the ventilator-dependent child.
3. Parents' groups should be formed to keep parents informed of their rights.
4. A national clearinghouse should be devised to provide parents with information about care and specific services for their children. There should be local community outlets for such a center.
5. Liaison should be developed with the community school system to allow for tutoring and entry, and, if possible, mainstreaming the child into the system.
6. Ongoing education experiences for the child and family must be provided by or arranged by the health providers.
7. Education of the child should be a part of the case management plan.

CATEGORY 9: RESEARCH

Basic research aimed at prevention of disability is of major importance. Research is needed also to define the problem more thoroughly and to investigate and evaluate possible solutions.

DEFINITION OF THE ISSUE AND ITS EFFECTS

We have very few programs for the delivery of care to the ventilator-dependent child that extend beyond the acute care unit of the tertiary center. We have presented the case for the benefits of care at home. As programs for these children evolve, careful research and evaluative studies must be conducted.

SUGGESTED STRATEGIES

1. Research should be undertaken in those factors which could improve the outcome of pregnancies.
2. Regional systems as they are developed should contain a research component.
3. Research on treatment interventions to measure outcomes should be undertaken.
4. Research is critical to measure cost effectiveness. There should be an immediate cost effectiveness study of the functioning programs in Pennsylvania, Illinois, and New York, with particular attention to the true dollar and social benefits of the various alternatives.
5. Research of other financial and reimbursement issues (e.g., prepayment plans) should be pursued.
6. Research should be undertaken to determine effective methods for education of professionals and for patient education.
7. Research is needed to establish qualifications necessary for personnel to participate in the management of ventilator-dependent children in various settings in a regional system.
8. Research should be an integral part of any of the strategies implemented as a result of this Workshop.

CATEGORY 10: FINANCING AND REIMBURSEMENT

Financial and reimbursement considerations are the overriding deterrents to the care of ventilator-dependent children in the least restrictive, most humane environments compatible with their medical needs.

DEFINITION OF THE ISSUE AND ITS EFFECTS

On a case-by-case basis, it has been demonstrated that considerable savings can be achieved by providing for the more satisfactory and humane care of ventilator-dependent children at home or in homelike alternatives in their communities. Unfortunately, our current private financial, insuring, and reimbursing systems did not evolve from a base designed for funding of care for children with chronic or long-term health problems. As the number of ventilator-dependent children increases, financing has to be restructured to deal with the new problems. The processes for paying expensive in-hospital acute care bills function fairly smoothly to certain limitations. On the other hand, the processes of funding community based care of ventilator-dependent children is uncoordinated, and in many situations, non-existent.

When a child is successfully transferred home, reimbursement becomes very complicated. A multitude of essential services is provided by a great variety of agencies, individuals, and vendors. The bills from all these sources are accumulated by the reimbursing party and must, in most cases, be analyzed and paid individually. Time is lost; statements are paid late; billing errors are common; both creditors and reimbursers become frustrated; and, as a result, the already difficult process of care at home becomes more cumbersome.

The reimbursement and financial systems for long-term community care of ventilator-dependent children need restructuring for flexibility and modernization.

SUGGESTED STRATEGIES

1. Work with major providers of third-party payment to improve reimbursement schedules.
2. Encourage maximum coordinated participation by government and private reimbursement agencies and in regional systems.
3. Develop methodology for advance reimbursement to families of children on care at home. Allocations of a specified amount of money should be made prospectively to be used over a finite period of time. Incentives should be built into this system to control costs.
4. As a corollary of the above, a new method of managing vouchers from individual service suppliers should be developed. Up-front money or bank accounts should be provided to allow for prompt payment of bills. Retrospective reimbursement should be eliminated or, at least, minimized.
5. Methods should be developed for "pool" purchase of equipment where that is found to be medically appropriate and more cost-effective.
6. Title V should play a major role in planning, promoting, and developing regionalized systems of care utilizing all available resources, rather than serving only as a third-party payer for small number of "eligible" children.
7. Financial counseling should be made available to the family.
8. Tax credits should be allowed for changes in the structure of the home which are necessitated by the child's disability.
9. The tax deductibility of medical expenses should be liberalized for families of patients on care at home.
10. Government requirements for "spend-down" should be minimized or eliminated.
11. Current policies and procedures for waiving Medicaid eligibility requirements should be kept in place.
12. Hospital cost containment processes should be encouraged and monitored to minimize the escalating cost to the system as a whole.
13. Coordination and management of services to children within a regional system of care should be recognized as essential; financing mechanisms should be developed.
14. Possibilities for arrangement of catastrophic illiness funding, disaster pools, or revolving accounts should be investigated.
15. The financial support system for ventilator-dependent children should be closely monitored and modified as necessary to prevent abuse.
16. All changes made in the financial support system for ventilator-dependent children should have as their underlying objective the attainment of the most humane care in the least restrictive environment and at the lowest cost.

CHILDREN WITH OTHER HANDICAPS

CHILDREN WITH DISABILITIES: IMPLICATIONS FOR CARE

Alfred Healy, M.D.

In November 1981, President Reagan cited the case of Katie Beckett, a 3 year old child, as an example of government regulations gone awry. Medicaid rules permitted payment for Katie's care in a highly intensive tertiary hospital but could not pay for care if Katie was taken home. President Reagan granted a waiver to permit payment for Katie's care at home.

The highly visible case of Katie Beckett publicized a health care delivery system that was not geared toward providing the best of life-sustaining technology in what we, in the area of services to the handicapped, would call "the least restrictive environment." The goal of providing services in the least restrictive environment is basically a humanitarian one. However, what has been most publicized about the case of Katie Beckett and similar ones is that this least restrictive environment is also often, dramatically, the least expensive one in which to provide services. What can we learn about health care delivery for this population of ventilator-dependent children, and how do the issues relate to our provision of services for handicapped children as a whole? Are there common elements to assist us in understanding the needs of children with disabilities?

First, we need to review both the children's health care system in general, and services to children with handicaps, as they exist in this country today, and then examine some of the factors that have influenced their development. Second, I would like to discuss a community-based evaluation and planning system for those children who have a high likelihood of living with restrictions on their functional lives—and to suggest methods we might use to reduce that likelihood.

Children's health care in this country is changing. Every person, whether provider or consumer, who has the opportunity to observe the process of health care delivery, or to measure its outcomes, must be impressed with the way the system has changed and continues to change in a very positive manner. Signs of positive change can be seen in increases in life expectancy and tremendous reductions in morbidity. Mention only needs to be made of poliomyelitis, erythroblastosis, and modern therapeutic approaches to childhood malignancy to confirm the occurrence of these changes.

Similarly, the status of children with disabilities in this country is changing. Those working with the education, therapy, counseling, housing, employment, or social needs of the handicapped—and with parents, neighbors, and friends of the disabled—are aware of the tremendous changes that have occurred in this field in the past two decades. Indicators of these changes include the early identification of those with disabilities and the removal of numerous barriers that interfere with opportunities for children with disabilities to become productive citizens.

Let's now review a few of the reasons why the health care system in general is evolving in this way. A number of trends have contributed to positive changes, including:

1. A significant increase in the availability of individual and personalized health care. The number of health care personnel has expanded and the fiscal and physical accessibility of health facilities has improved.
2. An increased personal involvement of patients and parents in assuming responsibility for their own health care. This involvement resulted from improved patient education and involvement in the decision-making process regarding the type and location of the required health service.
3. A recognition that services must be delivered or made available as close to the patient's home community as possible.
4. A realization that technical and human resources need to be targeted at patients with specific problems and that it is possible to measure accurately more subtle outcomes than mortality or gross morbidity.
5. An increased ability to move quickly from the research laboratory to clinical investigation followed by clinical application.

What then are the specific factors that assisted the growth and improvement of programs for some of the disabled, and how did those forces evolve?

1. Care became individualized. There was a shift in thinking from "All Down Syndrome children are alike," to "All Down Syndrome children require a continuum of evaluation services to document their individual strengths and deficits."
2. The settings for providing required services were critically examined and, in many instances, found to restrict the development of social, intellectual, and functional life skills. As a consequence, considerable numbers of children and adults moved from institutional settings and were placed in community-based residential homes and care facilities.
3. Parents and guardians became involved in decisions regarding their children's participation in educational programs and the provision of related services.
4. Patients and their parents or guardians were provided specific legal safeguards to ensure their participation in or knowledge of programs through such legislation as *PL 94-142, The Education for All Handicapped Children Act,* and Section 504 of the *Rehabilitation Act of 1973.*
5. Statewide planning for coordination of services was mandated, and specific accountability was required of states to ensure the delivery of services. These changes were seen in *PL 94-142* and in *PL 95-602, The Developmental Disabilities Act,* and in some aspects of the Health Block Grants.

6. Many programs were devised that implemented the interdisciplinary process, one that recognizes the need for a variety of professional expertise in the evaluation and care of disabled persons and that no one discipline has exclusive "rights" to a patient, irrespective of the problem or the "importance" of the discipline.

How do these trends in the health care system and the service system for the disabled relate to the problem facing this conference? What can we learn that will assist all handicapped children—and conversely, what elements of the care system for the disabled child can be applied to the problem of the ventilator-dependent child?

A cohort of children with respiratory conditions was identified that required a specific technological advance—the creation of appropriate respiratory life support systems so these children could lead independent lives. But the creation of the technological hardware did not resolve the clinical problem. The remaining problem is to identify successfully the social, political, educational, attitudinal and financial steps which will allow the available hardware to be placed in the hands of those children who desperately require it, and do so in a coordinated manner that does not burden the patient or the parent with overwhelming financial responsibilities. We also must provide this ventilatory assistance in a way that will least interfere with the child's developmental process. When we have minimized financial burdens and developmental interference, our system can be said to be operational. Our service delivery goals for the approximately seven to eight million other children who are labeled as handicapped in this country are very similar.

An important step in the achievement of these goals is the differentiation between a person who is disabled—one who has a condition or infirmity that interferes with life function—as opposed to a person with handicaps because either society or the person himself places barriers in the path of a functional life, barriers to living in "a least restrictive environment." Such barriers may be physical (the inability to enter a building in a wheel-chair because of a flight of stairs), discriminatory (the exclusion from qualified employment), or attitudinal (the lack of understanding of some health care financial underwriters that out-patient care may be less expensive and more useful in maintaining academic and social interests than in-hospital care).

Katie Beckett requires a ventilator for a health impairment, but she also desperately requires an environment in which to learn how to play and to delight in gaining developmental skills along with her peers. She requires an environment that will provide exciting sensory stimuli so she has facts and data to develop concepts and ideas, and she needs the opportunity to practice muscular skills so she may communicate with her world through the motor system. She also requires a nurturing and supportive social system—read "family" if at all possible—to surround her and react to her behavior so she may learn from her actions and those of her playmates.

We must not interpret "least restrictive environment" to mean "normal." Universal mainstreaming is as inappropriate as blanket institutionalization for disabled children. A home can be as restrictive as an institution if the child is not given every opportunity to develop. The bottom line

questions should be, is the child being given every opportunity to learn or develop inherent abilities and have we, as a responsible society, removed all barriers and placed the child in the most opportune setting for developmental interactions to occur?

In this country there are hundreds of ventilator-dependent children in tertiary care centers. Many of these children no longer need to be there. There are also hundreds of thousands of children in this country with health impairments or other disabling conditions who are alive today because of advances in scientific knowledge and its clinical application. Children with cystic fibrosis, hemophilia, arthritis, malignancies, muscular dystrophy, and other conditions now survive longer and demand full active participation in life. We have obligations to remove the barriers to active functional lives for all of these children.

These children and young adults with health impairments face similar problems in receiving known methods of optimal care, in the least restrictive environment. One barrier facing them is the inability of many health care personnel to recognize the need for a system to plan individualized non-hospital care for each patient in a manner that permits all social, health, education, and family resources to be parlayed into a continuum of care. This barrier is a common thread running through all care systems, including in-hospital care, but I wish to emphasize today the out-of-hospital need. This community need has been recognized for decades, but the solutions for implementation continue to escape those charged with ensuring access for all children to optimal community services. This need to use available community resources through effective communication and planning is especially important today when such a large percentage of in-hospital costs are due to utilization by a rather concentrated segment of all children, namely children with chronic disabilities restricting their functional life.

To function properly as part of the comprehensive services for handicapped children, a health care plan must consider the handicapped child not as a sick child but as a well child with a disability. There is still a tendency, even among some health professionals, to view the handicapped child as unwell and to see health care being performed in a segregated environment. A mentally retarded child, or a blind child, for example, may not have any unusual health-related problems. In other cases, the handicap itself may be health related, or may have chronic health-related aspects to it—such as in the case of the child with asthma or the child with spina bifida. In any case, the children are best and most economically cared for in the mainstream of the health care system, where they have access to the full range of primary, secondary, and tertiary services, not in a system set aside for the exclusive use of the handicapped.

It is especially important to understand that the comprehensive services required by children with handicaps will vary with the functional system or systems affected and the severity of the impairment. At birth, two percent of all liveborn infants have discernible handicapping conditions. By age five, approximately ten percent are considered handicapped. There must be a recognition that we require differing screening and identification systems with differing capabilities during that five-year period. We need to structure

a system that flows from a medical/nursing orientation for infants and toddlers under 30 months when almost all discernable or evolving handicaps are health-related, to a cognitive orientation with an educational perspective for the older child. This is a time when almost all new disabilities are related to the central processing system. Development-appropriate screening activities can then be provided that are cost effective and reduce duplication of effort. However, to be efficient, a process of communication must be established between the child's physician and the school during all such identification projects.

It must be remembered that during the elementary-school years, the majority of disabilities are related to the central processing system. Of the eight million handicapped individuals aged between birth and 21 years, only 20 percent have handicaps related to sensory deficits, motor disabilities, health impairments, or emotional disorders. The remaining 80 percent of all school-aged children with handicaps have mental retardation, learning disabilities, or language dysfunctions. Of this 80 percent, the majority have single system disabilities, those without complicating secondary disabilities that require a major coordination of services.

There are few, if any, studies to assist in understanding the percentage of children with disabilities who require primary, secondary, or tertiary level care of their health or medical needs. Discussions with experienced clinicians suggest that approximately 85 percent of all children with disabilities can be adequately cared for by primary care physicians communicating with the one "system" used by all children, the school. An additional 15 percent require referral to secondary physicians. Many have secondary complicating conditions that require coordinating functions between the primary referring physician and other community-based services or assistance agencies. Of the 15 percent requiring secondary level services, about one-third will also require, either occasionally or continuously, the medical or health care services of a tertiary center.

Approximately 85 percent of the health and medical needs for children with handicaps can be provided through the primary care system, aided by a modest level of communication between the physician and the school, as the physician provides ongoing health care supervision. Examples would include children with non-organic mental retardation, uncomplicated seizure disorders, or language dysfunctions. The primary care physician has a responsibility to ensure that all medically remediable aspects of the handicapping condition have been evaluated and treatment initiated if possible.

Secondary level health care and coordination of many health and non-health-oriented services is required by three groups:

1. Those children referred from primary care physicians for diagnostic services, or evaluation of complications from their original disability.
2. Those labeled health impaired—such as children with cystic fibrosis, hemophilia, juvenile rheumatoid arthritis, asthma, diabetes, cerebral palsy, or muscular dystrophy, of such a degree of severity they require a level of care greater than that available in the primary care system.

3. That group of children with complicated and interconnected health, social, and educational needs labeled as having "chronic conditions requiring long term care; of psychosocial and learning problems; behavioral and environmental effects; and problems related to family stress and parental actions and inactions. These problems require a multidisciplinary approach above and beyond traditional nursing and physician care." The basic need for this group is coordinated care as opposed to the direct provision of medical care.

Tertiary level care is required for that five percent with disabilities such as severe asthma, cystic fibrosis, cerebral palsy, muscular dystrophy, spina bifida, or similar conditions that require the expertise of those usually found in a medical center or university program. Irrespective that such care requires highly specialized personnel and sophisticated surgical and rehabilitative technology and treatment methods, the majority of the follow-up care to such tertiary care procedures is accomplished back in the local community using community resources. Studies have been accomplished that demonstrate cost efficiency when such community care is coordinated with that done in the tertiary center.

From these discussions, we can draw three important conclusions relating directly to the original question, "Will the disabled children of this country also continue to be handicapped?"

First, there is a constant need to recognize the concept of individual differences in all children—especially those with disabilities—so that they may receive appropriate services. Not all children with cerebral palsy should be programmed with the mentally retarded; not all ventilator-dependent children require the same system as Katie Beckett—if our system is to minimize financial burdens and minimally interefere with a disabled child's development.

Second, there is a need to structure a community-based system to coordinate the evaluation and planning of services for the fifteen percent of disabled children who have complicated or multifaceted disorders and to recognize that this entails more than medical or nursing care. There must be a smooth flow of information between all social, medical, educational, and family concerns; responsibility and accountability for providing and following up on services must be assigned and accepted.

Third, there must be a realization by all the remaining service providers, health planners, legislators, and health financiers, that such community-based evaluation and planning is necessary if barriers to maximum achievement for all disabled persons are to be removed.

There is no one uniform formula to guide individual communities toward such a system. Each state must review its individual health, education, and social service state plans that meet the state's individual geographic, political, and demographic needs; each state must work cooperatively to create a community-based system for those disabled children who require a coordinated evaluation and planning function.

This workshop is an important step toward developing such a system. Using the ventilator-dependent child as a focus for concentrated discussion

and planning will undoubtedly alert many persons to the need for the system. However, the larger effort must be in furthering communication between state Maternal and Child Health programs (including Crippled Children's Services), with state education agencies, local education agencies, and those professional organizations whose members have critical roles to play in formulating new methods of sharing evaluation and planning functions. This effort is currently underway in twelve states due to very innovative collaborative efforts funded by the Office of Maternal and Child Health and the Office of Special Education, and involving the American Academy of Pediatrics and the national network of University Affiliated Programs.

Other states have combined planning functions between State M and CH and State CC programs as they move to plan cooperatively and implement the provisions of block grants. Not surprisingly, state educational agencies are finding these extremely useful forums in which to participate and further mutual goals.

A last but extremely critical need is for each person attending this Workshop to realize the tremendous task remaining before us. Our task is to educate our fellow workers and to influence schools preparing psychologists, insurance executives, physicians, nurses, dentists, therapists, teachers, social workers, lawyers, business executives, and administrators about the needs discussed in this Workshop. Our personal actions can be multiplied a thousandfold if we accept the challenge of working with our University and Community College peers to include these concepts in their students' professional preparation and in the in-service education programs available to practicing professionals. In addition, we must share a similar education program with parents of disabled children and with the general public.

The best of available science was not able to prevent Katie from becoming disabled—even in the sophisticated, caring system currently in place. Conferences like this one should go a very long way to remove barriers that could bar her from enjoying a full productive life, barriers that could also make her become handicapped. Thank you for allowing me to share these thoughts with you today.

IMPLICATIONS FOR CARE: THE TITLE V PERSPECTIVE

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Title V programs have the legislative responsibility for providing health services to mothers and children. The Title V programs include the State Maternal and Child Health and the State Crippled Children's programs as well as the SPRANS (Special Projects of Regional and National Significance) programs. These programs include the pulmonary center, the genetic, the hemophilia, and other programs of regional and national significance. State programs have been designed to meet the particular needs of each individual State, and thus differ from each other. In addition, each of the SPRANS programs has its own agenda.

Those of us from State programs are not surprised that a new type of medical problem—that of the ventilator-dependent child—has been identified and that a proposal is made to provide services for the children so involved. The Federal-State public health programs for mothers and children have been developed over the years to provide new services for what were then new problems. The early regional programs to provide care for congenital heart disease, rheumatic fever prevention, cleft-palate, PKU identification, development of pediatric intensive care, hemophilia, and genetics programs were created when new problems were identified for which a form of treatment was available. Each of these programs was originally introduced at some type of meeting or conference similar to the one that we attend today.

Those of us from agencies involved with providing services for handicapped children also recognize that the services needed by the ventilator-dependent child are in many ways similar to those needed by hundreds of thousands of other disabled children in the nation. Thus, carefully developed programs meeting the needs of the ventilator-dependent child have been designed: so that the services are family oriented, multi-disciplinary, and coordinated. Each child has an individual plan of care, and some person is responsible to work with the family to assist in carrying out that plan of care so that the costs of the services do not destroy the family's finances. The goal of treatment is one of establishing as much personal independence as possible. These, of course, are the accepted principles of long-term care that have been tested and established during recent decades by those involved with providing services for children with continuing health problems.

Thus, the proposed programs providing services for the ventilator-dependent child differ from the current ones only in the technical nature and complexity of the services needed to address problems unique to these children. This should not surprise us. We are all aware of advances made in the last decades in the diagnosis of acute medical problems and in the difficult and technical forms of treatment. Many of these services may be so technical, however, that the current State Crippled Children's programs, designed to provide traditional services, may have difficulty in providing for these new technologies. This represents a major challenge to those of us

responsible for the design and administration of State programs. Title V programs must respond as they have responded to the development of new programs in the past, even though this may require major changes in the design of some State programs.

Many of us who are responsible for State Crippled Children's Programs have been concerned for some time that services for handicapped children have not evolved into a three-tiered system comparable to the three-tiered American medical care system. The exact role of the Title V programs and, more exactly, the Crippled Children's programs in such a three-tiered system is not clear.

It is apparent that State Crippled Children's Programs must work jointly with those who function in the tertiary care centers, since these centers provide much of the complex technical modern care and conduct research. Similarly, crippled children's programs must work closely with practicing physicians who provide secondary care. Historically, these programs have worked closely with the medical community and have made it possible for the State Crippled Children's programs to be the major subsystem for providing services for the disabled child. Crippled Children's programs must work even more closely with organizations and professionals who provide primary support services in the community.

Reference has been made to special demonstration projects jointly conducted by the Division of Maternal and Child Health and the Department of Education. These projects are exploring how children's services can best be coordinated in the community. The Crippled Children's programs can and should serve as the lead agency in the community to coordinate the network of services required by many children who have chronic health problems and can be involved with payment for those services for which they are responsible.

It would be very unfortunate if free-standing State categorical programs were created to provide services for the ventilator-dependent child. The creation of single disease programs has not proved to be a satisfactory long-term solution. State Title V programs, therefore, should have a significant part in the coordination of services required by ventilator-dependent children.

There is no doubt that our national goal should be access to needed services for all ventilator-dependent children, but the problem of implementing that goal will be very difficult. We must be realistic about the times in which we live. In current national policy, the States determine what public health programs should be provided based on the individual State's assessment of need and available resources. However, the great majority of States do not have in place a process or system to review the needs for health services. Most States are in great financial difficulties and are going to be very reluctant to assume the responsibility for new health programs.

Thus, implementation of the recommendations of this conference will require imagination in program organization and may require more political activity than those of us who are health providers wish to conduct. The Pennsylvania experience proves the possibility of obtaining state funds.

From the perspective of the Title V program, the basic question is how, at this time of public austerity, can we modify and coordinate health programs so we can provide contemporary medical care to the most children? Those of us responsible for Title V programs accept the challenge and will keep high on our agenda the special problems of the ventilator-dependent child.

IMPLICATIONS OF WORKSHOP RECOMMENDATIONS

This Workshop focusing on the ventilator-dependent child has given us a concrete and meaningful way to look at the needs of all children with disabilities and at the needs of their families. The ultimate value of the conference will be determined by its effect on those involved in the care of children with handicaps. The recommendations presented to the Surgeon General have implications for the care of all children with disabililties.

1. *Define the Scope of the Problem*

There remains a need to define better the numbers and types of disabilities experienced by infants, children, and young adults in this country and to better assess the impact on social, health, education, and family related needs. Considerable progress has been made in some areas but a system integrating functional, social, health, and family concerns remains to be defined, accepted, and consistently used by all service personnel and agencies. Needs are magnified when they occur during rapidly changing developmental periods in a child's life or when the child is desperately attempting to minimize the effects of the disability.

2. *Develop Model Standards*

Significant advances in health care for all children have been accomplished through the use of model guidelines and standards for health care. Examples include regionalized perinatal care and improved access to immunizations. These models and standards developed by a consensus of professional associations, were widely distributed and are now generally accepted. Similar models and standards must be developed to identify, evaluate, and provide coordinated care at all levels for persons with disabilities. Care standards for cohorts of disabled children with special needs must be superimposed on generic care standards for all children with disabilities. All standards must focus on family needs, with an eye for innovation and with compassion and concern for the quality of life for each disabled child. Careful consideration must be given to identifying methods of care that conserve and effectively use scarce fiscal and human resources.

3. *Develop Systems of Regionalized Care*

Matching the needs of disabled children with available resources will demand a system of care that reflects concern for generic social, educational, health, and family issues and that can focus on times of transition in disabled children's lives. Targets for concentration of resources will be determined by such factors as incidence, prevalence, and severity of the disability; location of the needed service, and other geographic and demographic characteristics of the population. Traditional methods may suffice for providing community based health care for infants, children, and young adults with relatively uncomplicated disabling conditions. However, regionalized

care will be required to assist those disabled children with complicated or life-threatening conditions, or who require highly specialized tertiary care.

4. *Improve Financing of Care*

The service system must adequately compensate providers and consumers using out-of-hospital facilities which are close to the patients' home community and which meet established care standards. Funding mechanisms must also be made available for expensive out-of-hospital technical equipment that reduces the length of hospital stays. Planning and coordination of community services for complicated and serious disabililties must be recognized as a legitimate reimbursable expense.

5. *Identify Areas of Abuse Potential*

Actions and inactions can both contribute to abuse of the care system for the disabled child. Elimination of unnecessary, duplicated or inappropriate services assure quality care and control costs. Standards and regulations must be developed and monitored by qualified professionals familiar with the service delivery issues. Methods to provide parents and providers with information or optimal services for children with disabilities must be an essential part of the regionalized system.

6. *Incorporate into Training Curricula Principles of Care For Children with Disabilities*

There is a need for the incorporation of clinical experiences relating to the care of disabled infants, children, and young adults into all levels of preservice and in-service education for health professionals. Utilization of interdisciplinary methods in the training process encourages coordinated clinical care. Teaching models should enhance professional satisfaction in caring for disabled children. Methods to improve communication skills among patients, parents, and fellow workers must be inherent components of the training program.

7. *Support Research in the Care of Children with Disabilities*

While our scientific understanding of specific disabling diseases and conditions is sophisticated, a great need remains to learn more about optimal methods of health care provision for disabled children. Research should include investigations into a) curricular revisions to better train professionals in evaluatory methods and treatment techniques; b) methods to enhance communication and coordinating skills; c) procedures to improve financial reimbursement procedures; d) methods to promote intra- and interagency understanding; and e) methods to immediately disseminate new information concerning the care of disabled children. Increasing concern for fiscal responsibility and accountability will dictate the wisdom of devoting significant portions of available resources to expand research and development endeavors.

65

SUMMARY OF THE WORKSHOP

In the summer of 1982, Surgeon General C. Everett Koop, M.D. requested that a Workshop on Children with Handicaps and their Families be convened to seek out ways to lessen the handicaps imposed on disabled children and to promote child and family self-sufficiency and autonomy. The workshop was held at The Children's Hospital of Philadelphia on December 13 and 14, 1982. Over 150 individuals, including handicapped patients, their families and those involved with their care, were invited to participate in the conference. An additional 100 people attended parts of the proceedings because of their interest in the welfare of handicapped children. All of the participants paid their own expenses or were supported by their own institutions. Financial assistance was provided for participating patients and parents.

The Workshop was called in response to the revolutionary transformations in medical technology which have taken place during the past four decades. Discoveries and applications in the fields of antibiotics and other drugs, in vaccines, in computerized imaging procedures, in life-support and monitoring, in laboratory techniques, and in the understanding of basic physiology have altered the prognosis for innumerable children. The baby who is born premature, the infant with severe congenital defects of the major organs or skeleton, and the child who is damaged by severe trauma or infection can now be supported by the combination of high technology and trained medical personnel. Many of these children now survive, and most of those who do can look forward to a productive life, though often impeded by residual disability.

Modern American society has geared itself to almost unlimited support of this technology. But support for the essential services systems outside the tertiary care environment has not kept pace for the increasing numbers of children whose lives are being saved. Technology is expensive, essential support services are also expensive, and funds are limited. Numbers of questions require consideration. Can we maintain the technological support, yet improve the essential services with the funds available? Do we need more funds? Can we find ways of redistributing the funds now being spent? Can we devise strategies for providing more humane service with fewer dollars?

Those attending the workshop concentrated on the severe, specific problems of the ventilator-dependent child, and the findings for this prototype were extrapolated for their implications for all handicapped children.

Dr. Robert G. Kettrick, Chairman of the Workshop, challenged the audience to accept responsibility for insuring that all reasonable care alternatives be made available for ventilator-dependent children. He asked them to identify and correct the circumstances which prevent transfer from an acute facility to home or community alternatives and presented a number of illustrated case histories representative of the progress which can be achieved by a child on home care.

Presentations of programs in Illinois, New York, and Pennsylvania explored problems and progress in meeting the needs of increasing numbers of ventilator-dependent children. A parent, Mrs. Betty Wartenberg, presented a summary of the life of her nine-year-old son. She gave an account that recalled the years on ventilator support in an intensive care unit, the disruptions to family unity, and of the remarkable progress made after his transfer to home care.

Following these presentations the participants were assigned to working groups where a mix of disciplines were used to assure an interchange of ideas and perspectives. Parents met insurance people, government executives saw and talked with handicapped patients who were in wheelchairs and on ventilators, executives of service organizations walked the acute and intermediate wards of the hospital and interacted with children who have lived there all their lives—3 or 4 years; legislative aides participated with physicians and hospital administrators. During this brief time a mechanism evolved which cut through the intermediaries of typed letters, impersonal phone calls, and layers of formalization. A consensus of the working groups' deliberations was reported to a final plenary session, which marked the close of the workshop.

SYNTHESIS OF THE DELIBERATIONS AND THE SURGEON GENERAL'S RESPONSE

The summaries and recommendations of the workshop groups reveal an overwhelming diversity of concepts and directions to be considered. Many ideas arose repeatedly during the two days of discussion and can be grouped within broad categories:

- Developing regional systems of care
- Defining the scope of the problem
- Developing model standards for quality assurance
- Incorporating principles of care for children with disabilities into current education curricula
- Identifying areas of potential abuse
- Supporting research on the care of children with handicaps
- Improving financing of the kinds of care these children and their families need

While the workshop did not focus specifically on ethical matters, the effect of each participant's set of social values was always apparent during discussions. Interaction was influenced by each person's values, conscious or not, stated or unstated. Throughout the process one quality—humaneness—permeated all. Humaneness, thus, was a common thread and a universal motivation. Every expression of thought seemed to emanate from the theme, "What is best for the child?"

In declaring the Workshop a success and accepting its recommendations, the Surgeon General praised the participants for their efforts and expressed his belief that the eventual outcome will be better health care for a more diverse group of children with disabilities. In his closing remarks, Dr. Koop assured the participants:

- That funds would be available for a small number of demonstration projects to develop the structure of a regionalized system;
- That a study of the national prevalence of ventilator-dependent children would be encouraged;
- That professional organizations would be encouraged to develop model standards for care;
- That public and private institutions will be encouraged to incorporate principles of care for ventilator-dependent children into their curricula;
- That abuses of resources will be identified and corrected;
- That those public and private agencies which fund research will be made aware of the issues presented at the Workshop; and
- That a primary focus of the federally-funded demonstration projects would be the issue of cost reimbursement from public, private, and voluntary sources; cost-reimbursement issues would continue to be discussed with insurers.

"Where we have it in our power, we hope to make their handicaps temporary, or, at least to ameliorate their severity. We will be using a variety of techniques to continue the momentum which has developed at the Workshop, and I will report back to you as we make progress on the various suggestions you have passed on to me as Surgeon General."

"The Department of Health and Human Services has a very strong commitment to improve services to disabled children and their families. And, as long as I am Surgeon General, disabled children have a very strong advocate in the Public Health Service."

APPENDIX A

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APPENDIX C

PROTOTYPE HOME PROGRAM REVIEW FOR VENTILATOR-DEPENDENT CHILDREN

The Children's Hospital of Philadelphia

I. GOALS
- To provide safe respiratory support within the home environment
- To resolve problems of cash flow for payment of services

II. INITIAL STAGE

A. Service Provision
- Consultation with institutions planning home care for the ventilator-dependent child
- Supervision of respiratory care of program participants
- Home visits by health care team
- Telephone access to health care team
- Referral to appropriate service agencies
- Coordination of inter-agency and family contract
- Development of resource list
- Development of parents' support group
- Coordination of consultative services, i.e., nutrition, respiratory therapy, rehabilitation, etc.
- Classification of nursing needs for third party payers
- Crisis intervention
- Supportive counseling (i.e., bereavement, effects of chronic illness on siblings, etc.)
- Liaison between Commonwealth of Pennsylvania—Department of Health and Welfare and families
- Liaison with vendors
- Disbursement of Commonwealth of Pennsylvania—Department of Health and Welfare funds in order to meet legislative intent of *Appropriation Act 17A of 1980*

B. Educational Services
- Development and supervision of family and home caregivers pre-discharge training program
- Provision of post-discharge parent education
- Education for parent advocacy
- Education for parent assertiveness
- Education of health professionals regarding home-care for ventilator-dependent children
- Liaison between families and school districts

C. Documentation and Investigation Needs
- Patient classification of nursing care needs
- Nursing assessment
- Developmental assessment
- Parents' Guide for Home Care
- Interview guide for parents when hiring home-care givers
- Nutritional assessment
- Pre-discharge Social Work Protocol
- Post-discharge Social Work Protocol
- Individual Service Plan
- Patient population survey
- Resource list for parents and professionals
- Documentation of program costs for ventilator-dependent children
- Documentation of family costs for the care of a ventilator-dependent child

D. Policy Guideline and Procedure Development
- Eligibility review
- Enrollment criteria
- Equipment and supply lists
- Motor vehicle accessory lists
- Purchase agreements for equipment
- Acquisition of capital equipment
- Reimbursement for electricity bills

III. SECONDARY STAGE

A. Service Provision
- Consultation with institutions planning home care for ventilator-dependent child
- Provision of nutrition consultant
- Provision of a home visit by a member of the home health care team at least annually
- 24-hour 7-day-a-week telephone access to medical personnel
- Education of parents about community service agencies and their services
- Provision of a forum for peer support
- Provision of and payment for services of home care personnel, i.e., nurses, respiratory therapists
- Provision of an objective analysis of nursing care needs for prescriptions and negotiation with third-party payers
- Exploration of resources for crisis intervention
- Exploration of local resources for supportive counseling
- Provision of library resource or bibliography on chronic illness and related effects
- Provision of expertise and cash flow to families for acquisition of capital equipment, disposable and non-disposable supplies for health care and rehabilitation needs
- Resolution of cash-flow dilemma
- Provision of payment for necessary care not reimbursable by established third-party mechanisms

- Liaison with third-party payers to investigate and consider cost-effectiveness of home care vs. long-term institutionalization

B. Educational Services
- Development of instruction manual for hospital use in educating and testing families in home health care of ventilator- and/or oxygen-dependent children
- Development of a parent organization
- Development of continuing education programs for health professionals involved in care of ventilator-dependent children
- Proper placement within an educational system

C. Documentation and Investigation Needs
- Resolution of conflict between families and third-party payers relative to appropriateness of nursing care
- Documentation of nursing needs
- Development of program for acquiring comprehensive nursing data base
- Documentation of developmental profiles
- Provision of hospital-based education to insure comprehensive education of families who will care for ventilator-dependent children
- Documentation of nutritional status and interventions
- Development of protocol for social workers who may be involved in discharge planning of ventilator-dependent children
- Development of a protocol for social workers involved in the home care of ventilator-dependent children
- Development of individual service plans for all children within the program
- Definition of the number of acute-care institutions currently involved in the care of ventilator-dependent children
- Development of family financial profiles
- Documentation of medical and social services not being met by third-party payers
- Definition of services mandated by existing State and Federal programs

D. Policy and Procedure Development
- Development of policies and procedures to provide uniform services to families enrolled in program

E. Contingency Planning
- Development of contingency plans to help families to deal with termination of money

IV. FINAL STAGE

A. Service Provision
- Institutionalize a program within the Commonwealth of Pennsylvania, Department of Health and Welfare to insure that the needs of ventilator- and/or oxygen-dependent children and their families are met

B. Educational Services
- Provide or insure access to an educational system as provided for by the Commonwealth of Pennsylvania and Federal Law (PL 94-142 and Rehabilitation Act of 1973 Section 504)
- Provide a comprehensive education program for professionals involved in the care of ventilator-dependent children
- Define a comprehensive continuing education program for families of ventilator-dependent children

C. Documentation and Investigation Needs
- Develop and prepare standards of care, costs, policies and procedures for the care of ventilator-dependent children
- Investigate and document advantages and disadvantages of disposition alternatives for ventilator-dependent children
- Investigate and document the effect of a ventilator-dependent child on family functioning

APPENDIX D

SELECTED READINGS

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